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ABSTRACT

The full hearing to amend the Developmental Disabilities Services and Facilities Construction Act to Revise and Extend the programs authorized by that Act and related Bill is presented. The full texts of S. 462, S. 1194, and J.R. 4005, three pieces of legislation proposing to revise and extend the Developmental Disabilities Act, are given and take up 515 pages of the document. S. Report 94-160 discusses background information, purposes, needs, and hearings regarding S. 462 and serves to accompany that legislation. It describes in detail Title I--Assistance for Persons with Developmental Disabilities and Title II--Bill of Rights for Mentally Retarded and Other Persons with Developmental Disabilities and provides a section by section analysis. Assistant Secretary for Legislation, DHEW, Stephen Kurzman's statements before the subcommittee regarding the various bills and disabilities programs are presented, as well as his responses to questions posed by members of the subcommittee. The full texts of prepared statements by various national organizations and related communications regarding S. 462 are included. (LH)

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DEVELOPMENTALLY DISABLED ASSISTANCE AND BILL OF RIGHTS ACT, 1975

HEARING

BEFORE THE

SUBCOMMITTEE ON THE HANDICAPPED

OF THE

COMMITTEE ON LABOR AND PUBLIC WELFARE UNITED STATES SENATE

NINETY-FOURTH CONGRESS

FIRST SESSION

ON

S. 462

TO AMEND THE DEVELOPMENTAL DISABILITIES SERVICES AND FACILITIES CONSTRUCTION ACT TO REVISE AND EXTEND THE PROGRAMS AUTHORIZED BY THAT ACT AND RELATED BILL

MARCH 18, 1975

Printed for the use of the Committee on Labor and Public Welfare

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DEVELOPMENTALLY DISABLED ASSISTANCE AND BILL OF RIGHTS ACT, 1975

TUESDAY, MARCH 18, 1975

U.S. Senate,
Subcommittee on Handicapped of the
Committee on Labor and Public Welfare,
Washington, D.C.

The subcommittee met, pursuant to notice, at 10:10 a.m., in room 4232, Dirksen Senate Office Building, Senator Jennings Randolph (subcommittee chairman), presiding.

Present: Senators Randolph and Stafford.

Senator Randolph. A pleasant morning to all of you at this hearing of the Subcommittee on the Handicapped of the Senate Labor and Public Welfare Committee. Senator Stafford and I will be present during the hearing, and we hope the schedules of other members will permit them to participate also.

We are gratified that our witness today is Stephen Kurzman, Assistant Secretary for Legislation of the Department of Health, Education, and Welfare. He is accompanied by Peter Franklin, Special Assistant to the Secretary, and Francis Lynch, Director, Division of Developmental Disabilities, Office for Human Development.

Today we consider S. 462, the Developmentally Disabled Assistance and Bill of Rights Act. As all of you are aware, S. 462 is the same as S. 3378, a bill which was reported unanimously from this Subcommittee to our Full Committee on Labor and Public Welfare, where it was also reported unanimously. It passed the Senate without a dissenting vote on October 1, 1974.

I regret that circumstances beyond control of this subcommittee made it impossible to complete action on this important legislation before the 93d Congress adjourned. I am sure that Senator Stafford, other members of the subcommittee, and even Members of the Senate, were disappointed in this delay of what we believed to be necessary legislation. I also share the disappointment, not only of the organizations who supported this bill, but, more importantly, the developmentally disabled Americans who benefit from its provisions.

In keeping with a commitment to ourselves, we have made this legislation the first order of business of our subcommittee. I introduced S. 462 on January 28, 1975. In a spirit of cooperation, we have scheduled this hearing to accommodate the Department of Health, Education, and Welfare, so that they can be heard on their new bill.

All of us are quite familiar with the provisions in S. 462. For the record, however, I think it would be helpful to all of us to have a brief review.

During the first session of the 93d Congress, the Developmental Disabilities Act was given a 1-year extension—to June 30, 1974—as part of an omnibus health bill because the Senate was awaiting the results of a General Accounting Office report evaluating the developmental disabilities program.

The Senate received the report in January 1974, and wrote legislation, S. 3378, which was targeted at correcting the inequities in and improving the program.

We desire, and I think the administration also desires, very much to improve the 1970 act.

New approaches in S. 462 include a major thrust in planning, coordination, and evaluation; the development of an outreach program of satellite centers by university-affiliated facilities; the establishment of a new, more cooperative relationship between the State developmental disabilities councils, the administering State agency, and the university-affiliated facilities; the development of an evaluation model which the States may use in setting up individual State evaluation systems; the strengthening of the State developmental disabilities councils and the National Advisory Council; the broadening of the definition of a developmental disability; and the placement of the Division of Developmental Disabilities in the Office of the Secretary of the Department of Health, Education, and Welfare.

Also incorporated are the provisions of S. 458, Senator Javits' bill of rights for the mentally retarded, as well as new language for alternative procedures and criteria which institutions and community facilities could meet in lieu of the criteria originally set forth in S. 458.

At this point we will include in the record copies of S. 462 and related bills.

[The texts of S. 462, S. 1194, and H.R. 4005 follow:]

94th CONGRESS
1st Session

S. 462

IN THE SENATE OF THE UNITED STATES

JANUARY 28, 1975

Mr. RANDOLPH (for himself, Mr. CRANSTON, Mr. HATHAWAY, Mr. HOLLINGS, Mr. HUMPHREY, Mr. JAVITS, Mr. KENNEDY, Mr. MONDALE, Mr. PELL, Mr. SCHWEIKER, Mr. STAFFORD, Mr. TAFT, and Mr. WILLIAMS) introduced the following bill; which was read twice and referred to the Committee on Labor and Public Welfare

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A BILL

To amend the Developmental Disabilities Services and Facilities Construction Act to revise and extend the programs authorized by that Act.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That this Act may be cited as the "Developmentally Disabled Assistance and Bill of Rights Act".

DEFINITIONS

SEC. 2. For purposes of title I of this Act—

(1) "Construction" means the construction of new buildings, the acquisition, expansion, remodeling, alteration, and renovation of existing buildings, and initial equipment

of any such buildings (including medical transportation facilities).

(2) "Cost of construction" means the amount found by the Secretary to be necessary for the construction of a project, including architect's fees, but excluding the cost of offsite improvements and the cost of the acquisition of land.

(3) "Design for implementation" means a document prepared by the appropriate State agency or agencies outlining the implementation of the State plan as developed by the State planning council. The design for implementation shall include details on the methodology of implementation, priorities for spending, a detailed plan for the use of funds provided under this Act, specific objectives to be achieved, a listing of those programs and resources to be utilized, and a method for periodic evaluation of its effectiveness in meeting State plan objectives.

(4) "Developmental disability" means a disability which is—

(A) attributable to mental retardation, cerebral palsy, epilepsy, autism, or to a specific learning disability; or

(B) attributable to any other condition of an individual found to be closely related to mental retardation as it refers to general intellectual functioning or impairment in adaptive behavior or to require treatment similar to that required for mentally retarded individuals, which disability (i) originates before such individual attains age 18, (ii) has continued or can be expected to continue indefinitely, and (iii) constitutes a substantial handicap to such individual's ability to function normally in society.

(5) "Institution of higher education" has the meaning given it in section 122(c) of the Education Amendments of 1972.

(6) "Nonprofit facility for persons with developmental disabilities", or "nonprofit private institution of higher learning" mean a facility for persons with developmental disabilities, and an institution of higher learning which is owned and operated by one or more nonprofit corporations or associations no part of the net earnings of which inures, or may lawfully inure, to the benefit of any private shareholder or individual.

(7) "Nonprofit private agency or organization" means an agency or organization which is a nonprofit corporation or association or which is owned and operated by one or more of such corporations or associations.

(8) "Poverty area" has the meaning given it in regulations of the Secretary.

(9) "Satellite center" means a facility of an agency or agencies associated with a university affiliated facility that functions as a community or regional extension of such uni-

versity affiliated facility in the delivery of training, services, and programs to the consumers or their representatives, the designated State delivery system agency, and other service or program delivery units.

(10) "Secretary" means the Secretary of Health, Education, and Welfare.

(11) "Services for persons with developmental disabilities" means specialized services or special adaptations of generic services directed toward the alleviation of a developmental disability or toward the social, personal, physical, or economic habilitation or rehabilitation of an individual with such a disability, and such term includes diagnosis, evaluation, treatment, personal care, day care, domiciliary care, special living arrangements, training, education, sheltered employment, recreation, counseling of the individual with such disability and of his family, protective and other social and legal services, information and referral services, follow-along services, and transportation services necessary to assure delivery of services to persons with developmental disabilities.

(12) "Specific learning disability" means a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which disorder may manifest itself in imperfect ability to listen, think, speak, read, write, spell, or do mathematical calcula-

tions, and such disorder may include such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, or developmental aphasia, but such term does not include learning problems which are primarily the result of visual, hearing, or motor handicaps, of mental retardation, or emotional disturbance, or of environmental disadvantage.

(13) "State", includes the several States, Puerto Rico, Guam, American Samoa, the Virgin Islands, the Trust Territory of the Pacific Islands, and the District of Columbia.

(14) "State planning council" means a council established in a State pursuant to section 115 of this Act.

(15) "Title" when used with reference to a site for a project, means a fee simple, or such other estate or interest (including a leasehold on which the annual rental does not exceed 4 percent of the value of the land) as the Secretary finds sufficient to assure for a period of not less than 50 years undisturbed use and possession for the purposes of construction and operation of the project.

AUDIT

SEC. 3. Each recipient of a grant or contract under this Act shall keep such records as the Secretary may prescribe, including records which fully disclose the amount and disposition by such recipient of the proceeds of such grant or contract, the total cost of the project or undertaking in connection with which such grant or contract is made or funds thereunder used, the amount of that portion of the cost of the project or undertaking supplied by other sources, and such records as will facilitate an effective audit. The Secretary and the Comptroller General of the United States, or any of their duly authorized representatives, shall have access for the purpose of audit and examination to any books, documents, papers, and records of the recipient of any grant or contract under this Act which are pertinent to such grant or contract.

OFFICE OF DEVELOPMENTAL DISABILITIES

SEC. 4. There is established in the Office of Secretary an Office of Developmental Disabilities headed by a Director to carry out the purposes of this Act.

ADVANCE FUNDING

SEC. 5. (a) For the purpose of affording adequate notice of funding available under this Act, appropriations under this Act are authorized to be included in the appropriation Act for the fiscal year preceding the fiscal year for which they are available for obligation.

(b) In order to effect a transition to the advance funding method of timing appropriation action, the authority provided by subsection (a) of this section shall apply notwithstanding that its initial application will result in the enactment in the same year (whether the same appropriation Act or otherwise) of two separate appropriations, one for the then current fiscal year and one for the succeeding fiscal year.

EMPLOYMENT OF HANDICAPPED INDIVIDUALS

SEC. 6. As a condition of providing financial assistance under this Act, the Secretary shall ensure that each recipient of such assistance shall take affirmative action to employ and advance in employment qualified handicapped individuals covered under and on the same terms and conditions as set forth in, the applicable provisions of the Rehabilitation Act of 1973 (87 Stat. 355) relating to employment of handicapped individuals by State rehabilitation agencies and rehabilitation facilities and under Federal contracts and subcontracts.

TITLE I—ASSISTANCE FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

DECLARATION OF PURPOSE AND FEDERAL SHARE

SEC. 100. (a) The purpose of this title is to improve and coordinate the provision of services to persons with developmental disabilities through (A) grants to assist the several States in developing and implementing a comprehensive and continuing plan for meeting the current and future needs of persons with developmental disabilities; (B) the renovation and modernization of university-affiliated facilities which aid in demonstrating the provision of specialized services for persons with developmental disabilities, through support of demonstration and training programs at institutions of higher education; (C) the development of regional community programs for services to persons with developmental disabilities; (D) the support of activities which will contribute to improving the condition of persons with developmental disabilities, including but not limited to grants for demonstrating exemplary services to persons with developmental disabilities who are especially disadvantaged; (E) technical assistance in the establishment of services and facilities for persons with developmental disabilities, including assistance in State and local planning or administration; (F) training of specialized personnel needed for the provision of services to persons with developmental disabilities; and (G) developing or demonstrating new or improved techniques for the provision of services to persons with developmental disabilities.

(b) The Federal share with respect to any project assisted under part A of this title may not exceed 70 percent of the necessary cost thereof as determined by the Secretary.

(c) The Federal share with respect to assistance under part B of this title may not exceed 70 percent of the necessary cost thereof as determined by the Secretary, except that with respect to a project of any facility or agency which provides, or will upon completion of a project assisted under such part B provide, services to a poverty area, the

Federal share may not exceed 90 percent of the necessary cost thereof.

(d) (1) The non-Federal share of the cost of any project assisted under this title shall be provided in cash and not in kind.

(2) Payments of grants under this title shall be made in advance or by way of reimbursement, and on such conditions as the Secretary may determine.

(3) For the purpose of determining the Federal share with respect to any State, expenditures by a political subdivision thereof or by nonprofit private agencies, organizations, and groups shall, subject to such limitations and conditions the Secretary may by regulation prescribe, be deemed to be expenditures by such State.

PART A—DEMONSTRATION AND TRAINING GRANTS FOR UNIVERSITY AFFILIATED FACILITIES AND RENOVATION AND CONSTRUCTION OF FACILITIES

RENOVATION AND CONSTRUCTION

SEC. 101. (a) For the purpose of making grants under subsection (b) there is authorized to be appropriated $6,500,000 for the fiscal year ending June 30, 1975, and for each of the next four succeeding fiscal years.

(b) Amounts appropriated pursuant to subsection (a) shall be used only for project grants for (1) renovation or modernization of a university affiliated facility which is carrying out a program under section 102 (a) or (2) renovation and modernization of a facility to be operated as a satellite center (as defined in section 2 (9)) of a university affiliated facility. Amounts appropriated pursuant to subsection (a) shall be used only with respect to facilities which after renovation and modernization meet standards adopted pursuant to the Architectural Barriers Act of 1968 (82 Stat. 718).

(c) The Secretary in making grants for the purposes of subsection (b) (2) of this section shall give a priority to those applicants utilizing existing facilities.

DEMONSTRATION, TRAINING, AND OPERATIONAL GRANTS

SEC. 102. (a) (1) The Secretary shall, in accordance with the provisions of this part, make grants to university affiliated facilities to pay part of the cost of administering and operating demonstration facilities and interdisciplinary training programs for personnel needed to render specialized services to persons with developmental disabilities, with emphasis upon the ability and commitment of such programs to provide services not otherwise available under other laws to persons with developmental disabilities in programs of community care as alternatives to such services being provided in institutional settings.

(2) Each recipient of a grant made under paragraph (1) (if funds are available in accordance with paragraph

(3)) shall conduct a study and submit to the Secretary (not later than six months after the date of receipt of such grant) a full report which includes—

(A) an assessment of the need for the provision of alternative community care services for persons with developmental disabilities in each State not served by such recipient in the general geographical area in which such institution is located, and

(B) a feasibility study of ways in which such recipients, singly or together with other such recipients, could establish and operate satellite centers in areas described in subparagraph (A) to provide such services in coordination with demonstration facilities and interdisciplinary training programs assisted under paragraph (1).

(3) Assessments and studies required under the provisions of paragraph (2) shall be carried out in consultation with the State planning council for the State where the recipient is located and where the satellite center would be established, and may be carried out jointly with one or more recipients under paragraph (1). The Secretary, subject to the availability of funds, shall include in the grant made under paragraph (1) an additional amount (not in excess of $25,000) necessary to pay all of the cost of any such assessment and study.

(b) (1) The Secretary may, in accordance with the provisions of this part, make grants to university affiliated facilities to pay part of the costs of establishing, administering, and operating satellite centers meeting the specifications developed in the assessments and studies carried out under paragraph (2) of subsection (a) of this section. Any recipient of assistance under this subsection may provide, by contract, for the operation of any satellite center assisted under this subsection by a qualified public or nonprofit private agency or organization. The non-Federal share for a grant under this subsection shall be provided by the State in which the satellite center will be located.

(2) For the purposes of this subsection only, the term "university affiliated facility" means a facility constructed under funds authorized by Public Law 88-164 to promote interdisciplinary training of personnel to serve developmentally disabled individuals, or a successor facility as designated by the Secretary to perform the functions of such facility.

(c) For the purpose of making grants pursuant to this section, there is authorized to be appropriated for the fiscal year ending June 30, 1975, and for each of the four succeeding fiscal years, $25,000,000, of which, in the fiscal year ending June 30, 1975, amounts appropriated in excess of $4,250,000 and not in excess of $4,975,000 (or such lesser amount as the Secretary may determine to be necessary) shall be made available only for the purposes of carrying out assessments and studies under paragraph (2) of subsection (a) of this section. With respect to amounts appropriated for the fiscal year ending June 30, 1976, and for subsequent fiscal years, $4,250,000 shall be available only for grants under paragraph (1) of subsection (a) of this section, and of amounts appropriated in excess of $4,250,000 for each such year, 50 percent shall be available only for grants under subsection (b) of this section.

APPLICATIONS

SEC. 103. (a) The Secretary may approve an application for a grant under this part only if the application contains or is supported by reasonable assurances that—

(1) the proposal for such renovation or modernization is consistent with the appropriate State plan established pursuant to section 114, and that the applicant will provide the services and training required by such State plan or plans as appropriate;

(2) the facility is associated, to the extent prescribed in regulations by the Secretary, with an institution of higher learning, a medical center (including affiliated health or education facilities), or with part of such an institution of higher education;

(3) the plans and specifications for such renovation or modernization are in accord with regulations prescribed by the Secretary under section 119;

(4) title to the site for the project is or will be vested in the State in which it is located, or in one or more of the agencies or institutions making the application, or in a public or nonprofit agency or institution which is to operate the facility;

(5) the non-Federal share will be available for renovation or modernization of the project and adequate funds will be available for its maintenance and operation when completed;

(6) the facility will comply with regulations of the Secretary relating to minimum standards of construction and equipment (promulgated with particular emphasis on securing compliance with standards adopted pursuant to the Architectural Barriers Act of 1968 and with regulations of the Secretary of Labor relating to occupational health and safety standards); and

(7) any laborer or mechanic employed by any contractor or subcontractor in the performance of work on any construction aided by payments pursuant to any grant under this section will be paid wages at rates not less than those prevailing on similar construction in the locality as determined by the Secretary of Labor in accordance with the Davis-Bacon Act, as amended (40 U.S.C. 276a–276a–5); and the Secretary of Labor shall have, with respect to the labor standard specified

in this paragraph, the authority and functions set forth in Reorganization Plan Numbered 14 of 1950 (15 F.R. 3176) and section 2 of the Act of June 13, 1934, as amended (40 U.S.C. 276c).

(b) (1) In considering applications for such grants under this part, the Secretary shall require that such applications demonstrate that the grant application has been reviewed and commented on by the State planning councils, and with respect to grants to university affiliated facilities, give priority to any application which shows that the applicant has made arrangements, in accordance with regulations of the Secretary for a junior college or other community-based educational or health facility to participate in the programs for which the application is made.

(2) In the event that a State planning council fails to complete its review and comment within thirty calendar days after the submission of such application to the council under this subsection, the applicant may submit directly to the Secretary a request to approve its application. If the Secretary finds that the failure by such council is arbitrary, capricious, or unwarranted, he may approve such application without further action by such council. In a case where the findings of the Secretary do not meet the criteria of the preceding sentence, he shall return such application to the State planning council for action.

(c) Applications for assistance under this part shall establish as priority goals—

(1) deinstitutionalization of persons with developmental disabilities including prevention of institutionalization, normalization outside of institutions, development of community-based programs including placement, and follow-up services;

(2) early screening, diagnosis, and evaluation of developmentally disabled infants and preschool children (including maternal care, developmental screening, home care, infant and preschool stimulation programs, and parent counseling and training);

(3) counseling, program coordination, follow-along services, protective services, and personal advocacy on behal[illegible]velopmentally disabled adults; and

(4) normalization of institutional life.

RECOVERY

SEC. 104. If any facility with respect to which Federal assistance has been provided under this part shall, at any time within 20 years after the completion of construction, renovation or modernization—

(1) be sold or transferred to any person, agency, or organization which is not qualified to file an application under this part, or

(2) cease to be a public or other nonprofit facility for persons with developmental disabilities,

the United States shall be entitled to recover from either the transferor or the transferee (or, in the case of a facility which has ceased to be a public or other nonprofit facility for persons with developmental disabilities, from the owners thereof) an amount bearing the same ratio to the then value (as determined by the agreement of the parties or by action brought in the district court of the United States for the district in which the facility is situated) of so much of the facility as constituted an approved project or projects, as the amount of the Federal participation bore to the cost of the construction of such project or projects. The Secretary, in accordance with regulations prescribed by him, may, upon finding good cause therefore, release the applicant or other owner from the obligation to continue such facility as a public or other nonprofit facility for persons with developmental disabilities.

MAINTENANCE OF EFFORT

SEC. 105. Applications for grants under this part may be approved by the Secretary only if the application contains or is supported by reasonable assurances that the grants will not result in any decrease in the level of State, local, and other non-Federal funds for services for persons with developmental disabilities and training of persons to provide such services which would (except for such grant) be available to the applicant, but that such grants will be used to supplement, and, to the extent practicable, to increase the level of such funds.

PART B—GRANTS FOR PLANNING, PROVISION OF SERVICES, AND CONSTRUCTION AND OPERATION OF FACILITIES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

AUTHORIZATION OF APPROPRIATION

SEC. 111. For the purpose of making grants to carry out this part, there are authorized to be appropriated $50,000,000 for the fiscal year ending June 30, 1975, $85,000,000 for the fiscal year ending June 30, 1976, $95,000,000 for the fiscal year ending June 30, 1977, $100,000,000 for the fiscal year ending June 30, 1978, and $110,000,000 for the fiscal year ending June 30, 1979; and there is further authorized to be appropriated for such purpose for each such fiscal year such additional sums as the Congress may deem necessary.

STATE ALLOTMENTS

SEC. 112. (a) (1) From the sums appropriated pursuant to section 111 for each fiscal year, other than amounts reserved by the Secretary for projects under subsection (e) of this section, the several States shall be entitled to allotments determined, in accordance with regulations, on the basis of (A) the population, (B) the extent of need for services and facilities for persons with developmental disabilities, and (C) the financial need, of the respective States; except that the allotment of any State (other than the Virgin Islands, American Samoa, Guam, and the Trust Territory of the Pacific Islands) for any such fiscal year shall be not less than $200,000 (except that no State shall receive less than the amount such State received for the fiscal year ending June 30, 1974, under section 132 (a) (1) of the Mental Retardation Facilities Construction Act (84 Stat. 1317)) and the allotment of the Virgin Islands, American Samoa, Guam, and the Trust Territory of the Pacific Islands shall be not less than $50,000 plus, for each fiscal year ending after June 30, 1975, for which appropriations exceed $50,000,000, an amount which bears the same ratio to $200,000 (or in the case of the Virgin Islands, American Samoa, Guam, or the Trust Territory of the Pacific Islands, $50,000) as the difference between the amount so appropriated for each fiscal year and $50,000,000 bears to $50,000,000.

(2) In determining, for purposes of paragraph (1), the extent of need in any State for services and facilities for persons with developmental disabilities, the Secretary shall take into account the scope and extent of the services specified, pursuant to section 114 (b), in the State plan of such State approved under this part.

(3) Sums allotted to a State for a fiscal year and designated by it for construction, renovation, or modernization which are unobligated at the end of such year shall remain available to such State for such purpose for the next fiscal year and for such year only, in addition to the sums allotted to such State for such fiscal year.

(b) Whenever a State plan is approved in accordance with section 114 which provides for participation of more than one State agency in administering or supervising the administration of designated portions of such plan, the State may apportion its allotment among such agencies in a manner which is reasonably related to the responsibilities assigned to such agencies in carrying out the purposes of this part, subject to the approval of the Secretary. Funds so apportioned to State agencies may be combined with other State or Federal funds authorized to be expended for other purposes, provided the purposes of this part will receive proportionate benefit from the combination.

(c) Whenever a State plan approved in accordance with section 114(c) provides for cooperative or joint effort between States or between or among agencies, public or private, in more than one State, portions of funds allotted to one or more such cooperating States or agencies may be combined in accordance with the agreements between the agencies and States involved.

(d) The amount of an allotment to a State for a fiscal year which the Secretary determines will not be required by the State during the period for which it is available for the purpose for which it is allotted shall be available for reallotment by the Secretary on such date or dates as he may fix (but not earlier than thirty days after he has published notice of his intention to make such reallotment in the Federal Register), to other States with respect to which such a determination has not been made, in proportion to the original allotments of such States for such fiscal year, but with such proportionate amount for any of such other States being reduced to the extent it exceeds the sum the Secretary estimates such State needs and will be able to use during such period; and the total of such reductions shall be similarly reallotted among the States whose proportionate amounts were not so reduced. Any amount so reallotted to a State for a fiscal year shall be deemed to be a part of its allotment under subsection (a) for such fiscal year.

(e) Of the sums appropriated pursuant to section 111, such amount as the Secretary may determine, but not more than 10 percent thereof, shall be available to the Secretary who, after consultation with the National Council established pursuant to section 113, may (notwithstanding the provisions of subsection (c) of section 100) make grants to States and public or nonprofit private agencies to pay up to

90 percent of the cost of projects which in his judgment are of special national significance. Such projects shall include—

(1) integrated service model projects for services to the developmentally disabled population,

(2) public awareness and public education programs to assist in the elimination of attitudinal and environmental barriers confronted by individuals with developmental disabilities, and

(3) demonstration projects to coordinate and utilize all available community resources,

in meeting the needs of persons with developmental disabilities (especially the disadvantaged), or will demonstrate new or improved techniques for the provision of services for such persons, or are otherwise specifically significant for carrying out the purposes of this part.

(f) The Secretary shall administer grants under this part in accordance with policies used generally to administer grants throughout the Department of Health, Education, and Welfare.

NATIONAL COUNCIL ON SERVICES AND FACILITIES FOR THE DEVELOPMENTALLY DISABLED

SEC. 113. (a) (1) Effective thirty days after the date of enactment of this Act, there is established in the Office of the Secretary a National Council on Services and Facilities for the Developmentally Disabled (herein referred to as the "National Council"), whose membership shall include the Deputy Commissioner of the Bureau of Education for the Handicapped, the Commissioner of the Rehabilitation Services Administration, the Administrator of the Social and Rehabilitation Service, the Director of the National Institute of Child Health and Human Development, the Director of the National Institute of Neurological Disease and Stroke, the Director of the National Institute of Mental Health, three other representatives of the Department of Health, Education, and Welfare selected by the Secretary, and sixteen members, who are not full-time employees of the United States, to be appointed by the Secretary without regard to the provisions of title 5, United States Code, governing appointments in the competitive civil service.

(2) The Secretary shall from time to time designate 1 of the 16 appointed members of the National Council to serve as Chairman thereof.

(3) The 16 appointed members of the National Council shall be selected from advocates in the fields of service to persons with developmental disabilities, including leaders in State or local government, in institutions of higher education, and in organizations which have demonstrated advocacy on behalf of consumers of such services. At least 5 such members shall be representatives of State or local public

or nonprofit private agencies responsible for services to persons with developmental disabilities, and at least 5 other such members shall be consumers of such services or the parents or guardians of such consumers.

(b) Each appointed member of the National Council shall hold office for a term of 4 years, except that any member appointed to fill a vacancy occurring prior to the expiration of the term for which his predecessor was appointed shall be appointed for the remainder of such term. A former member may only be reappointed to the National Council after a period of 1 year has elapsed from the end of his appointed term. The Secretary shall fill all vacancies resulting from the expiration of members' terms on the National Council within 10 calendar days of the occurrence of such vacancies.

(c) The National Council shall meet at least twice a year, and shall hold its initial meeting within 90 days after the date of enactment of this Act.

(d) It shall be the duty and function of the National Council to—

(1) advise the Secretary with respect to any regulations promulgated or proposed to be promulgated by him in the implementation of the provisions of this title;

(2) study and evaluate programs authorized by this title to determine their effectiveness in carrying out the purposes for which they were established;

(3) monitor the development and execution of this title and report directly to the Secretary any delay in the rapid execution of this title;

(4) review grants made under section 112(e) and advise the Secretary with respect thereto;

(5) review grants and contracts entered into pursuant to section 121, including review of the final evaluation system and advise the Secretary with respect thereto; and

(6) submit to the Congress annually an evaluation of the efficiency of the administration of the provisions of this title.

(e) The National Council is authorized to engage such technical assistance as may be required to carry out its functions, and the Secretary shall, in addition, make available to the National Council such secretarial, clerical, and other assistance and such statistical and other pertinent data prepared by or available to the Department of Health, Education, and Welfare as it may require to carry out such functions.

(f) Members of the National Council, while attending meetings or conferences thereof or otherwise serving on the business of the National Council, shall be entitled to receive compensation at rates fixed by the Secretary, but at rates not exceeding the daily equivalent of the rate provided for GS-18 of the General Schedule for each day of such service (including traveltime), and while so serving away from their homes or regular places of business, they may be allowed travel expenses, including per diem in lieu of subsistence, as authorized by section 5703 of title 5, United States Code, for persons in the Government service employed intermittently.

(g) A member of the National Council created pursuant to section 133 of the Developmental Disabilities Services and Facilities Construction Amendments of 1970 whose term has not expired by July 1, 1974, shall continue to serve as a member of the National Council established in this section until the date such term would have expired had such Act remained in effect after July 1, 1974.

(h) There are authorized to be appropriated to carry out the purposes of this section $100,000 for the fiscal year ending June 30, 1975, and for each of the four succeeding fiscal years.

(i) The National Council shall cease to exist as of June 30, 1979.

STATE PLANS

SEC. 114. (a) For each fiscal year in which a State makes application to participate in programs under this part it shall develop, submit, and obtain the approval of the Secretary of an annual State plan which is a specific goal oriented plan, which shall include provisions designed to—

(1) reduce and eventually eliminate inappropriate institutional placement of persons with developmental disabilities;

(2) improve the quality of care, habilitation, and rehabilitation of persons with developmental disabilities for whom institutional care is appropriate;

(3) provide early screening, diagnosis, and evaluation of developmentally disabled infants and preschool children (including maternal care, developmental screening, home care, infant and preschool stimulation programs, and parent counseling and training);

(4) provide counseling, program coordination, follow-along services, protective services, and personal advocacy on behalf of developmentally disabled adults;

(5) support the establishment of community programs as alternatives to institutionalization, designed to provide services for the care and habilitation of persons with developmental disabilities, which programs utilize, to the maximum extent feasible, the resources and personnel in related community programs to assure full coordination with such programs and to assure the provision of appropriate supplemental health, educational or social services for persons with developmental disabilities;

(6) protect the human rights of all persons with developmental disabilities, especially those without familial protection; and

(7) provide for interdisciplinary intervention and training programs for multihandicapped individuals.

Such annual State plan shall be initially submitted within one hundred and eighty days after the date of enactment of this Act.

(b) Before the Secretary may approve a State plan under subsection (c) of this section, the appropriate State planning council shall approve the design for implementation (including its plan for expenditure of funds) contained within such State plan. A State plan for the provision of services and facilities for persons with developmental disabilities shall—

(1) designate—

(A) the State agency or agencies (except as provided in clause (B)) which shall administer and supervise the administration of the State plan, and if there is more than one such agency, the portion of such plan which each will administer (or the portion the administration of which each will supervise); and

(B) a single State agency as the sole agency for administering or supervising the administration of grants for construction, renovation, or modernization under the State plan;

(2) describe the quality, extent, and scope of services being provided or to be provided to meet the goals specified in subsection (a) of this section;

(3) describe (A) the quality, extent, and scope of services being provided, or to be provided, to persons with developmental disabilities under such other State plans for federally assisted State programs as may be specified by the Secretary, which shall in any case include education for the handicapped, vocational rehabilitation, public assistance, medical assistance, social services, maternal and child health, crippled children's services, and comprehensive health and mental health plans, and (B) how funds allotted to the State in accordance with section 112 will be used to complement and augment rather than duplicate or replace services and facilities for persons with developmental disabilities who are eligible for Federal assistance under such other State programs;

(4) provide for the maximum utilization of all available community resources including volunteers serving under the Domestic Volunteer Service Act of 1973 (87 Stat. 394) and other appropriate voluntary organizations;

(5) set forth policies and procedures for the expenditure of funds under the plan which, in the judg-

ment of the Secretary, are designed to assure effective continuing State planning, evaluation, and delivery of services (both public and private) for persons with developmental disabilities;

(6) contain assurances satisfactory to the Secretary that (A) the funds paid to the State under this part will be used to make a significant contribution toward strengthening services for persons with developmental disabilities in the various political subdivisions of the State in order to improve the quality, scope, and extent of such services; (B) part of such funds may be made avaliable to other public or nonprofit private agencies, institutions, and organizations; (C) such funds will be used to supplement and, to the extent practicable, to increase the level of funds that would otherwise be made available for the purposes for which the Federal funds are provided and not to supplant such non-Federal funds; and (D) there will be reasonable State financial participation in the cost of carrying out the State plan;

(7) provide that services and facilities furnished under the plan for persons with developmental disabilities will be in accordance with standards prescribed by regulations of the Secretary pursuant to this title and title II of this Act;

(8) provide such methods of administration, including methods relating to the establishment and maintenance of personnel standards and selection and advancement of personnel on a merit basis, as are found by the Secretary to be necessary for the proper and efficient operation of the plan (except that the Secretary shall exercise no authority with respect to the selection, tenure of office, and compensation of any individual employed in accordance with such methods);

(9) provide assurances that the State planning council is assigned adequate personnel in order to insure that such council has the capacity to fulfill its responsibilities in the areas of planning, resource development, and program evaluation;

(10) provide that the State planning council shall periodically, but not less often than annually, review and evaluate the State plan and submit appropriate modifications to the Secretary for his approval;

(11) provide that the State agencies designated pursuant to paragraph (1) of this subsection will make such reports, in such form and containing such information, as the Secretary or the State planning council may from time to time reasonably require, and will keep such records and afford such access thereto as the Secretary

finds necessary to assure the correctness and verification of such reports;

(12) provide that special financial and technical assistance shall be given to areas of urban or rural poverty in providing services and facilities for persons with developmental disabilities who are residents of such areas;

(13) describe the methods to be used to assess the effectiveness and accomplishments of the State in meeting the needs of persons with developmental disabilities in the State;

(14) specify the maximum amount of, and the percentage of the State's allotment under, section 112 for a centage of the State's allotment under, section 112 for any year which is to be devoted to construction, renovation, or modernization of facilities, which percentage shall be not more than 10 percent of the State's allotment or such lesser percentage as the Secretary may from time to time prescribe;

(15) if Federal funds are allotted for construction, renovation, or modernization under this part, outline a program of construction, renovation, or modernization of facilities for the provision of services for persons with development disabilities which—

(A) is based on a statewide inventory of existing facilities and survey of need;

(B) sets forth the relative need, determined in accordance with the regulations prescribed by the Secretary for the several projects included in the construction, renovation, or modernization program; and

(C) assigns priority to the construction, renovation, or modernization of projects, to the extent that financial resources available therefor and for maintenance and operation permit such priority, in the order of relative need, taking into account the requirement that any such construction, renovation, or modernization complies with any standards prescribed pursuant to the Architectural Barriers Act of 1968;

(16) provide for an opportunity for hearing before the State agency to every applicant for a construction, renovation, or modernization project;

(17) provide for such fiscal control and fund accounting procedures as may be necessary to assure the proper disbursements of, and accounting for, funds paid to the State under this part in accordance with regulations the Secretary shall prescribe;

(18) provide for the implementation of an evaluation system compatible with the system developed under

section 121 of this Act, within 30 months after the date of enactment of this Act;

(19) provide, to the maximum extent feasible, an opportunity for prior review and comment by the State planning council of all State plans in the State which relate to programs affecting persons with developmental disabilities;

(20) provide that personnel assigned to the State planning council shall be solely responsible to such council;

(21) provide that all relevant information concerning any programs which may affect persons with developmental disabilities shall be made available by projects and State agencies to the State planning council; and

(22) contain such additional information and assurances as the Secretary may determine to be necessary to carry out the provisions and purpose of this part.

(c) The Secretary shall approve any State plan and any modification thereof which complies with the provisions of subsection (b) of this section. The Secretary shall not disapprove a State plan unless he has provided reasonable notice and opportunity for a hearing to the State.

STATE PLANNING COUNCILS

SEC. 115. (a) Each State which receives assistance under this title shall establish a State planning council which shall serve as advocate for persons with developmental disabilities, and whose members shall be appointed by the Governor of each such State.

(b) The State planning council shall—

(1) develop and prepare the State plan required by section 114;

(2) approve, monitor, and evaluate the implementation of such State plan and submit to the Governor and the State legislature an annual report on such implementation;

(3) establish priorities for the distribution of funds for programs for persons with developmental disabilities within the State;

(4) review and comment on all State plans in the State which relate to programs affecting persons with developmental disabilities; and

(5) submit to the Secretary, through the Governor, such periodic reports on its activities as the Secretary may reasonably request.

(c) Each State receiving assistance under this title shall provide for the assignment to the State Planning Council of personnel adequate to insure that such council has the capacity to fulfill its responsibilities in the areas of planning, resource development, and program evaluation, except that funds provided for such council personnel shall be at least at a level equal to 20 percent of the amount of the State's allotment under section 112, but not more than 30 percent of such amount.

(d) Each State Planning Council shall at all times include in its membership representatives of the principal State agencies, local agencies, and nongovernmental agencies, and groups concerned with services to persons with developmental disabilities, including a representative of an institution of higher education receiving a grant under this title and servicing a facility within that State and at least one-third of the membership of such council shall consist of consumers of such services, or their parents or guardians, who are not officers of any organization, or employees of any State agency, or other agency or facility, which receives funds or provides services pursuant to this Act.

(e) The State agency or agencies designated under section 114(b)(1)(A) shall submit to the State planning council for its approval the design for implementation, including a detailed plan for the disbursement of all funds under this part (except as otherwise provided by this part).

(f) The Secretary shall insure that each State planning council has access to all other State plans submitted to him under section 114, as well as any relevant statistical and fiscal information relating to persons with developmental disabilities.

APPROVAL OF PROJECTS FOR CONSTRUCTION, RENOVATION, OR MODERNIZATION

SEC. 116 (a) Any State or political subdivision thereof or a public or nonprofit private agency shall, with respect to any project for construction, renovation, or modernization authorized under this part, submit an application therefor to the Secretary, through the State agency designated pursuant to section 114 (b) (1) (B) (herein in this part referred to as the "State agency"). An application for a project to be completed by two or more political subdivisions or public or nonprofit private agencies, or by a combination thereof, may be submitted by one such agency on behalf of all of them. Such application shall set forth—

(1) a description of the site for such project;

(2) plans and specifications thereof, in accordance with regulations prescribed by the Secretary;

(3) satisfactory assurances that title to such site is or will be vested in one or more of the agencies filing the application or in a public or nonprofit private agency which is to operate the facility;

(4) satisfactory assurances that the non-Federal share of financial support will be available for the construction, renovation, or modernization of the project and for its maintenance and operation when completed;

(5) a certification by the State agency of the Federal share for the project;

(6) satisfactory assurances that the project, facility, or activity, in connection with which such determination is made, does, or when completed or put into operation, will serve the needs of the residents of the area;

(7) a certification by the State agency that the project will comply with any standards prescribed pursuant to the Architectural Barriers Act of 1968; and

(8) satisfactory assurances that such construction, renovation, or modernization will conform to the requirements of section 103 (b) (7) of this Act.

(b) The Secretary shall approve an application under this section if sufficient funds to pay the Federal share of the cost of such project are available from the allotment to the State, and if the Secretary finds that the application—

(1) sets forth, to his satisfaction, the information required in subsection (a),

(2) is in conformity with the State plan approved under this part, and

(3) has been approved and recommended by the State agency and is entitled to priority over other projects within the State in accordance with the State's plan for persons with developmental disabilities and in accordance with regulations prescribed by the Secretary.

(c) No application shall be disapproved until the Secretary has afforded the State agency adequate notice and an opportunity for a hearing.

(d) Amendment of any approved application shall be subject to approval in the same manner as the original application.

WITHHOLDING OF PAYMENTS

SEC. 117. (a) Whenever the Secretary, after reasonable notice and opportunity for hearing to a State planning council and a State agency or agencies designated pursuant to section 114 (b) (1) finds—

(1) that any such State agency or agencies are not complying with the provisions required by section 114 (b) to be included in the State plan, or with regulations of the Secretary;

(2) that a State, State agency, or State planning council are not in compliance with the provisions of section 115;

(3) that any requirement set forth in an application submitted under section 114 and approved by the Secretary is not being or cannot be carried out with respect to the project for which such application was submitted;

(4) that there is a substantial failure to carry out plans and specifications related to construction, renova-

tion, or modernization approved by the Secretary, under section 116; or

(5) that adequate funds are not being provided annually for the direct administration of the State plan,

the Secretary may forthwith notify such State council and State agency or agencies that—

(A) no further payments will be made to the State for construction, renovation, or modernization from allotments under this part; or

(B) no further payments will be made from allotments under this part for any project or projects designated by the Secretary as being affected by the action or inaction referred to in paragraph (1), (2), (3), (4), or (5) of this subsection as the Secretary may determine to be appropriate under the circumstances; and, except with regard to any project for which the application has already been approved and which is not directly affected, further payments for construction, renovation, or modernization projects may be withheld, in whole or in part, until the Secretary is satisfied that the State has corrected any deficiencies under this subsection or, if such correction is impossible, until the State repays or arranges for the repayment of Federal moneys to which the State was not entitled because of such deficiencies.

(b) Whenever the State planning council finds that a State agency administering funds pursuant to the implementation design is failing to comply with such design, the State planning council shall notify the Governor and the Secretary, who may provide notice, conduct a hearing, and withhold payments pursuant to subsection (a) of this section.

PAYMENTS TO THE STATES FOR PLANNING ADMINISTRATION AND SERVICES

SEC. 118. From each State's allotment for a fiscal year under section 112, the State shall be paid the Federal share of its expenditures, other than expenditures for construction, renovation, or modernization, incurred during such year under its State plan approved under this part. Such payments shall be made from time to time in advance on the basis of estimates by the Secretary of the sums the State will expend under the State plan, except that such adjustments as may be necessary shall be made on account of previously made underpayments or overpayments under this section.

REGULATIONS

SEC. 119. (a) The Secretary, not later than 90 days after the date of enactment of this Act, shall prescribe general regulations in final form applicable to all the States to carry out the purposes of this title.

(b) (1) Regulations promulgated by the Secretary may be waived upon approval of an application submitted by a

State for a project to be completed by two or more political subdivisions or public or nonprofit private agencies, or by a combination thereof, which is consistent with applicable law and regulations promulgated by the Secretary for such purposes to provide services to persons with developmental disabilities by combining funds received from other Federal, State, or local programs to the extent that such regulations would without such waiver impede the implementation of such project. Such waivers shall be reviewed annually by the Secretary and issued on a case-by-case basis and for a specified period of time, but in no case longer than thirty-six months. Renewal of such waivers may be granted only after a full evaluation of the impact of such waivers by the Secretary. The Secretary shall submit his justifications for any renewal of such waivers in a report to the appropriate committees of the Congress.

(2) The Secretary shall publish in the Federal Register the fact that an application for waiver under paragraph (1) has been submitted by a State, and he shall not approve or disapprove such application for a period of not less than 60 nor more than 90 days after the date of such publication.

NONDUPLICATION

SEC. 120. (a) In determining the amount of any payment for the construction, renovation, or modernization of any facility under a State plan approved under this part, there shall be disregarded (1) any portion of the costs of such construction, renovation, or modernization which are financed by Federal funds provided under any provision of law other than this part, (2) the amount of any non-Federal funds provided under any provision of law other than this part, and (3) the amount of any non-Federal funds required to be expended as a condition of receipt of such Federal funds.

(b) In determining the amount of any State's Federal share of expenditures for planning, administration, and services incurred by it under a State plan approved under this part, there shall be disregarded (1) any portion of such expenditures which are financed by Federal funds provided under any provision of law other than this part, and (2) the amount of any non-Federal funds required to be expended as a condition of receipt of such Federal funds.

EVALUATION OF DEVELOPMENTAL DISABILITIES SERVICES

SEC. 121. (a) The Secretary, in consultation with the National Council created pursuant to section 113 of this Act, shall develop and transmit to the appropriate committees of Congress, within 18 months after the date of enactment of this section, an evaluation system and plan for implementation of such system which shall provide a model for the development of State evaluation systems for all services delivered within the States to persons with developmental disabilities.

(b) The evaluation system required by subsection (a) shall be designed to—

(1) assess the adequacy of all education and training, habilitation, rehabilitation, early childhood, diagnostic and evaluation services, and all other services or assistance to persons with developmental disabilities under laws administered by the Secretary; and

(2) develop specific criteria designed to provide objective measurement of the developmental progress of persons with developmental disabilities, which may be utilized by public agencies, residential facilities, and community-based facilities and agencies to evaluate the effectiveness of the services provided to such persons.

(c) In developing such evaluation system the Secretary shall insure that such system is consumer oriented and that the system will—

(1) evaluate the effects of services on the lives of consumers, utilizing information and data obtained from individualized written habilitation plans as required under section 211 of this Act (when applicable) or other comparable individualized data,

(2) evaluate the overall impact of State and local programs for the developmentally disabled,

(3) provide and evaluate the cost-benefit ratios of particular service alternatives, and

(4) provide that evaluation of program quality shall be performed by individuals not directly involved in the delivery of such services to the program being evaluated.

(d) The Secretary, in consultation with the National Council, may make grants to, and enter into contracts with, private nonprofit organizations or individuals to conduct feasibility studies to assist in developing the evaluation system required under subsection (a), except that such grant or contract shall not be entered into with groups or individuals who have any financial or other direct interest in the program being evaluated.

(e) There are authorized to be appropriated to carry out the purposes of this section $1,000,000 for the fiscal year ending June 30, 1975, and $1,000,000 for the fiscal year ending June 30, 1976.

GRANTS FOR SPECIAL PROJECTS FOR SERVICES TO PERSONS WITH DEVELOPMENTAL DISABILITIES

SEC. 122. (a) For the purpose of making grants under this section for special projects and demonstrations (and research and evaluation connected therewith), there is authorized to be appropriated $17,500,000 for the fiscal year ending June 30, 1975, $20,000,000 for the fiscal year ending June 30, 1976, $22,500,000 for the fiscal year ending June 30, 1977, $25,000,000 for the fiscal year ending June 30, 1978, and $27,500,000 for the year ending June 30, 1979.

(b) The Secretary, after consultation with the National Council, shall make grants to States and public or nonprofit agencies and organizations to pay part or all of the cost of special projects and demonstrations (and research and evaluation in connection therewith) for establishing programs which hold promise of expanding or otherwise improving services to persons with developmental disabilities (especially those who are disadvantaged or multihandicapped). Such projects and demonstrations shall include, but not be limited to, parent counseling and training, early screening and intervention, infant and preschool programs, seizure control system, legal advocacy, and community based counseling, care, housing, and other services or systems necessary to maintain a person with developmental disabilities in the community.

(c) The Secretary shall insure that any such special projects are approved or disapproved by the appropriate State planning council within 30 days after such council receives the application for review.

(d) Projects, or a component of any project funded under this section, shall not be eligible for funding under section 304 of the Rehabilitation Act of 1973 (87 Stat. 381).

REPEAL

SEC. 123. Effective 90 days after enactment, parts B and C of the Developmental Disabilities Services and Facilities Construction Act (42 U.S.C. 2661) are repealed.

TITLE II—BILL OF RIGHTS FOR MENTALLY RETARDED AND OTHER PERSONS WITH DEVELOPMENTAL DISABILITIES

STATEMENT OF PURPOSE

SEC. 200. The purpose of this title is to establish standards to assure the humane care, treatment, habilitation, and protection of mentally retarded and other persons with developmental disabilities who are served by residential and community facilities and agencies; to establish a method to assess compliance with such standards; and to minimize inappropriate admissions to such facilities and agencies, through the establishment of a method for assuring that the standards affecting the health, safety, personal dignity, and human and civil rights of persons with developmental disabilities are being complied with by such facilities or agencies; and through (1) (A) the use of procedural criteria set forth in part B of this title and performance based criteria developed by the Secretary pursuant to section 210 of this Act; (B) compliance with minimum standards set forth in section 215; and (C) such additional specific criteria that the Council and the Secretary may deem necessary; or (2) compliance with standards set forth in parts C and D of this title.

PART A—GENERAL PROVISIONS FOR RESIDENTIAL AND COMMUNITY FACILITIES AND AGENCIES SERVING MENTALLY RETARDED AND OTHER PERSONS WITH DEVELOPMENTAL DISABILITIES

DEFINITIONS

SEC. 201. For the purposes of this title—

(1) "adaptive behavior" means the effectiveness or degree with which the individual meets the standards of personal independence and social responsibility which is normal in relation to his age and social and cultural environment;

(2) "agency" means a public or nonprofit organization that provides services to persons with mental retardation and other developmental disabilities, or to their families, but which need not limit its services to developmentally disabled persons, and may provide services to developmentally disabled persons as part of services provided to the general public;

(3) "body image" means the concept that each person has of his or her own body as an object in space, independent of and apart from all other objects, including one's attitudes, perceptions, and feelings toward his or her body and its parts;

(4) "client", "person", "disabled person", or "disabled" means a person or individual who is mentally

retarded or otherwise developmentally disabled, and who needs some form of specialized or generic service related to his mental or physical impairment;

(5) "program coordinator" means an individual who is responsible for the implementation of the individual program plan, and who participates in the regular evaluation, revision, and redirection of the individual program plan;

(6) "community" means a general population having a common interest or interdependency in the delivery of services to mentally retarded or other persons with developmental disability;

(7) "cross-disciplinary approach" means a method of delivering services in which one or two members of an interdisciplinary team serve as team facilitators to implement the program plan between regularly scheduled reevaluation sessions by the team, and in which other members of the team teach and share their specialized professional skills with, and release their intervention role to, such facilitators during such implementation, while maintaining their professional (or credentialed) accountability on behalf of the person and his family;

(8) "culturally normative" means that which is normal, typical, or usual for a given culture, including the attitudes, performances, or behavior ordinarily displayed

by, or expected of, most individuals within a given culture;

(9) "family" means parents, brothers, sisters, foster parents, advocates, guardians, surrogates, and others who perform the roles and functions of natural family members in the lives of persons;

(10) "generic services" means services offered or available to the general public, as distinguished from specialized services that are intended only for mentally retarded or other developmentally disabled persons;

(11) "governing board", "board of trustees", "board of directors", or "board of governors" means the group of individuals that constitutes the governing body of an agency or facility;

(12) "governing body" means the policymaking authority, whether an individual or a group, that exercises general direction over the affairs of an agency or facility and that establishes policies concerning its operation and the welfare of the persons that it serves;

(13) "guardian" means an individual (other than a guardian ad litem) who has legal control and management of the person, or of the property or estate, or of both the person and the property, of a ward;

(14) "guardian of the person" means a guardian appointed to see that the ward has proper care and protective supervision in keeping with his needs;

(15) "guardian of the property" means a guardian appointed to see that the financial affairs of the ward are handled in his best interests;

(16) "legal guardian" means a guardian appointed by a court;

(17) "natural guardian" means a parent lawfully in control of the person of his or her minor child, and such natural guardianship terminates when the child attains his or her majority;

(18) "plenary guardian" means a guardian who has full guardianship of both the person and the property of the ward;

(19) "public guardian" means a public official empowered to accept court appointment as a legal guardian;

(20) "testimony guardian" means a guardian designated by the last will and testament of a natural guardian;

(21) "guardian ad litem" means an individual appointed to represent a ward in a particular legal proceeding, without control over either the ward's person or his estate;

(22) "indigenous leadership" means leadership that is derived from within the community or group in which it is exercised, as, for example, leadership that is de-

rived from within the community or group in which it is exercised, as, for example, leadership that is derived from the parents or friends of the person;

(23) (A) "informed consent" means the consent of a person, or his guardian or legal representative, as appropriate, to a procedure, operation, research, demonstration, or experiment, so situated as to enable such person, or through his guardian or legal representative to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, or other form of constraint or coercion, and the information to be given to such person or such guardian or legal representative shall include, in order to assure such informed consent, the following basic elements in all but exceptional cases;

(i) a fair explanation of the procedures to be followed, including an identification of any which are experimental;

(ii) a description of any attendant discomforts and risks reasonably to be expected;

(iii) a description of any benefits reasonably to be expected;

(iv) a disclosure of any appropriate alternative procedures that might be advantageous for the subject;

(v) an offer to answer any inquiries concerning the procedures; and

(vi) an instruction that such person is free to withdraw his consent and to discontinue participation in the project or activity at any time;

and, in addition, any agreement, written or oral, entered into by such person or his guardian or legal representative, shall include no exculpatory language through which such person is made to give, or to appear to waive, any of his legal rights, or to release the institution or its agents from liability for negligence. Any organization which initiates, directs, or engages in programs of research, development, or demonstration which require informed consent shall keep a permanent record of each such consent and the information provided such person and shall develop appropriate documentation and reporting procedures as an essential administrative function;

(B) "exceptional cases", as used in this section, are cases where it is not feasible to obtain a person's consent or the consent of his representative, or where, as a matter of professional judgment exercised in the best interest of a particular person under care, it would be contrary to that person's welfare to obtain his consent as the communication of information to obtain consent would seriously affect the person's disease status and the physician has exercised a professional judgment that under the particular circumstances of this person's case, the person's best interests would suffer if consent were sought;

(24) "interdisciplinary approach" means an approach to diagnosis, evaluation, and individual program planning in which professional and other personnel participate as a team, and in which each participant, utilizing whatever skills, competencies, insights, and perspectives his or her particular training and experience provide, focuses on identifying the developmental needs of the person and devising ways to meet them, without constraints imposed by assigning particular domains of behavior or development to particular disciplines only, and participants share all information and recommendations, so that a unified and integrated habilitation program plan is devised by the team;

(25) "multidisciplinary approach" means an approach to diagnosis, evaluation, and individual program planning in which each representative of a particular discipline or program views the person only from the perspective assigned to his discipline or program; in which particular domains of individual development and behavior are often held to be the sole responsibility

or perquisite of particular professions or programs; and in which each representative of a discipline separately reports his or her findings and the recommendations that he or she proposes to implement as a result, more or less independently of the findings and recommendations reported by other representatives;

(26) "mapping" means one's ability to move safely, effectively, and comfortably from one place to another within his or her immediate environment by using cues such as size, shape, odor, and landmarks;

(27) "mental retardation" means significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior, and manifested during the developmental period;

(28) "mobile nonambulatory" means an inability to walk independently, without assistance;

(29) "nonambulatory" means an inability to walk independently, without assistance;

(30) "normalization principle" means the principle of helping mentally retarded and other developmentally disabled individuals to obtain an existence as close to the normal as possible, particularly through the use of means that are as culturally normative as possible to elicit and maintain behavior that is as culturally normative as possible;

(31) "orientation" means the establishing of awareness of one's position in relation to the environment and significant objects within the environment;

(32) "program" means a structured set of activities to achieve specific objectives, relative to the developmental needs of the clients served by an agency;

(33) "residential facility" means a facility that provides 24-hour programing services, including residential or domiciliary services, directed to enhancing the health, welfare, and development of persons with mental retardation or other developmental disabilities;

(34) "service delivery system" means the total array of service components, specialized and generic, that is directed toward meeting the general and extraordinary needs of developmentally disabled persons;

(35) "advocate" means an individual, whether a professional employed by a private or public agency, or a volunteer, who acts on behalf of a resident to secure both the services that the resident requires and the exercise of his or her full human and legal rights;

(36) "ambulatory" means able to walk independently, without assistance;

(37) "chief executive officer" means the individual appointed by the governing body of a facility to act in its behalf in the overall management of the facility (job

titles may include, but are not limited to, superintendent, director, and administrator);

(38) "developmental disability" means a disability—

(A) attributable to mental retardation, or cerebral palsy, or epilepsy, or autism, or specific learning disability; or

(B) attributable to any other condition of an individual found to be related to mental retardation as it refers to general intellectual functioning or impairment in adaptive behavior or to require treatment similar to that required for mentally retarded individuals,

which disability (i) originates before such individual attains age eighteen, (ii) which has continued or can be expected to continue indefinitely, and (iii) which constitutes a substantial handicap to such individual's ability to function normally in society;

(39) "direct-care staff" means individuals who conduct the resident-living program;

(40) "legal incompetence" means the legal determination that a resident is unable to exercise his or her full civil and legal rights, and that a guardian is required;

(41) "living unit" means a resident-living unit that includes sleeping, dining, and activity areas;

(42) "nonmobile" means unable to move from place to place;

(43) "public financial support programs" include, but are not limited to, services for crippled children; aid to the disabled; old-age, survivors, and disability insurance; and other benefits available under the Social Security Act and those benefits of the Veterans' Administration;

(44) "resident" means an individual who receives service from a residential facility, whether or not such individual is actually in residence in the facility, and includes individuals who are being considered for residence in a facility, individuals who were formerly in residence in a facility, and individuals who are receiving services other than domiciliary from a facility;

(45) "resident-living" means residential or domiciliary services provided by a facility;

(46) "rhythm of life" means a normal pattern of behavior during the day (in respect to arising, getting dressed, participating in play and work activities, eating meals, retiring, and so forth), or the week (differentiation of daily activities and schedules);

(47) "surrogate" means an individual who functions in lieu of a resident's parents or family; and

(48) "time out" means a period outside the time of positive reinforcement in which, contingent upon the emission of undesired behavior, the resident is removed from the situation in which positive reinforcement is available.

NATIONAL ADVISORY COUNCIL ON STANDARDS FOR RESIDENTIAL AND COMMUNITY FACILITIES FOR MENTALLY RETARDED AND OTHER PERSONS WITH DEVELOPMENTAL DISABILITIES

SEC. 202. (a) Effective 90 days after the date of enactment of this Act, there is established a National Advisory Council for Residential and Community Facilities (hereinafter in this title referred to as the "Council"), which shall consist of 15 members who are not regular full-time employees of the United States, to be appointed by the Secretary without regard to the provisions of title 5, United States Code, governing appointments in the competitive civil service. The Secretary shall designate one of the members of the Council to serve as Chairman thereof. The members of the Council shall be selected from appropriate public agencies providing services to individuals with developmental disabilities, and professional and voluntary associations representing developmentally disabled persons. At least one-third of the membership of the Council shall be consumers of services, including parents or guardians of persons receiving services from publicly operated and publicly assisted residential and community facilities and agencies for mentally retarded or developmentally disabled persons.

(b) It shall be the duty and function of the Council to (1) advise the Secretary with respect to any regulations promulgated or proposed to be promulgated by him for the implementation of the provisions of this title and of the standards established under parts C and D of this title, (2) study and evaluate such provisions and standards, including site visits and other appropriate methods with a view of determining their effectiveness in carrying out the purposes for which they were established, and (3) assist the Secretary in developing performance criteria to evaluate alternate standards pursuant to part B and section 121 of this Act in lieu of standards under parts C and D of this title.

(c) Based upon studies, evaluations, and other appropriate review mechanisms (including onsite visits), the Council shall submit to the Secretary all recommendations for changes, revisions, modifications or improvements in the standards established under parts C and D of this title which in its judgment would strengthen or upgrade such standards.

(d) Members of the Council while attending meetings or conferences thereof or otherwise serving on the business of the Council, shall be entitled to receive compensation rates fixed by the Secretary, but at rates not exceeding the daily equivalent of the rate provided for GS-18 of the General Schedule for each day of such service (including traveltime), and, while so serving away from their homes or regular places of business, they may be allowed travel expenses, including per diem in lieu of subsistence, as authorized by section 5703 of title 5, United States Code, for persons in the Government service employed intermittently.

(e) Appointments to fill vacancies on such Council shall be made not less than 30 days after a vacancy occurs.

(f) The Council shall employ such experts and consultants as it may require, in accordance with section 3109 of title 5, United States Code.

(g) There are authorized to be appropriated to carry out the purposes of this section such sums as may be necessary.

ASSESSING COMPLIANCE WITH STANDARDS

SEC. 203. (a) In determining whether any federally assisted facility or agency within its jurisdiction is in compliance with the standards specified in this title, a State shall provide assurances to the Secretary within 1 year after the date of enactment of this title that each such facility or agency has established a plan for achieving compliance no later than 5 years after the date of enactment of this title, and—

(1) is actively pursuing a program to comply with standards set forth in parts C and D of this title, or

(2) meets the requirements set forth in part B of this title.

In order to further demonstrate compliance with the standards set forth in this title, a State shall submit to the Secretary a plan based upon the combined plans of all such facilities and agencies which sets forth detailed procedures for compliance and under which such State agrees to meet such provisions for compliance reviews as the Secretary may require pursuant to subsection (d) of this section.

(b) Each State plan for achieving compliance required under section (a) shall—

(1) provide a detailed analysis of the steps each residential or community facility or agency will take to comply with standards under part B, or parts C and D;

(2) set forth a detailed schedule for compliance with such standards based on the analysis submitted pursuant to clause (1);

(3) demonstrate the need for continuing residential services and provide detailed assurances that residential facilities for individuals with developmental disabilities will complement and augment rather than duplicate or

replace other community services and facilities for individuals with developmental disabilities which meet the requirements of this title;

(4) designate a single State agency to oversee compliance by facilities and agencies within its jurisdiction;

(5) provide that such State plan has been submitted to the State planning council established under section 115 of this Act for review and comment and has been found to be in conformance with the State plan required under section 114 (b) of this Act;

(6) set forth a schedule of costs to achieve compliance with the standards established under part B or parts C and D of this title;

(7) demonstrate procedures adopted by the State to assure that primary emphasis will be given to placing each individual in the least restrictive program and living environment commensurate with that individual's capabilities and needs, and that any assistance available pursuant to State or Federal law under which services are provided to persons with developmental disabilities will be utilized to foster the carrying out of such procedures;

(8) set forth the detailed performance criteria to be used in assessing the quality of treatment, care, training, and habilitation services, provided that such

criteria conform to criteria developed by the Secretary under section 210;

(9) provide an explanation of the system to be used for gathering, analyzing, and interpreting information and data for compliance review; and

(10) provide assurances that all subjective judgments concerning the quality of services rendered will be made by qualified individuals who are not employed by, or financially obligated to, the agency responsible for operating the programs for persons with developmental disabilities.

(c) The Secretary shall approve a plan which sets forth a reasonable time, subject to the provisions of section 206, for compliance with the standards established under this title, and shall not finally disapprove a plan except after reasonable notice and opportunity for a hearing to such State.

(d) (1) Each State shall enter into an agreement with the Secretary under which the services of the State agency designated pursuant to paragraph (4) of subsection (b) will be utilized on his behalf for the purpose of determining whether a residential or community facility or agency is in compliance with standards established under part B or parts C and D of this title. Such determination shall be made on the basis of onsite surveys conducted by the State agency. Any State agency which has such an agreement may furnish to such facilities and agencies such specialized consultation services as may be needed to meet one or more of the standards established under this title. Any such services furnished by the State agency shall be deemed to have been furnished pursuant to such agreement. Within 90 days following the completion of each survey, the Secretary shall make public in readily available form the findings of each such survey.

(2) In order to assure compliance with the standards under part B or parts C and D and the performance criteria developed and established pursuant to section 210, the Secretary shall conduct a statistically valid, independent compliance survey of facilities and agencies within each State to determine the accuracy of information and data submitted pursuant to subsection (b) and paragraph (1) of this subsection.

(3) The Secretary shall submit annually to the appropriate committees of the Congress an annual report summarizing—

(A) the number and types of facilities and agencies, by State, found to be in compliance with the standards specified in part B, or parts C and D of this title;

(B) the number and types of facilities and agencies, by State, found not to be in compliance with the standards specified in part B, or parts C and D of this title;

(C) the reasons for noncompliance and the steps being taken by each State to assure that such facilities and agencies comply in the future with such standards;

(D) the findings of validation surveys conducted or commissioned by the Secretary in accordance with paragraph (1);

(E) the number and types of facilities and agencies, by State, which have been found by the Secretary to be ineligible for Federal assistance because of failure to comply with standards under this title; and

(F) recommendations for alterations in the compliance review system (including changes in performance criteria developed and established pursuant to section 210) and the supporting evidence for such alterations or change.

GRANTS TO ASSIST COMPLIANCE

SEC. 204. (a) The Secretary is authorized to make grants to assist States in bringing publicly operated and federally assisted residential or community facilities and agencies into compliance with the appropriate standards established under this title.

(b) For the purpose of making grants under this section, there are authorized to be appropriated for each fiscal year such sums as may be necessary.

(c) Any State applying for a grant under this section shall provide detailed information to the Secretary which shows how such grant will assist in meeting the standards established under this title.

(d) (1) The total of the grants with respect to any project under this part may not exceed 75 percent of the necessary cost thereof as determined by the Secretary.

(2) Payments of grants under this part shall be made in advance or by way of reimbursement, and on such conditions as the Secretary may determine.

MAINTENANCE OF EFFORT

SEC. 205. (a) In any fiscal year the Secretary may make Federal assistance payments authorized under any Federal law, to any publicly operated or publicly assisted facility for the developmentally disabled only if such facility provides specific evidence that such payments have not resulted in, or will not result in, any decrease in the per capita State and local expenditures for services for individuals with developmental disabilities which would otherwise be available to such facility. Such evidence shall include a detailed fiscal report, containing such information and in such form as the Secretary may specify after consultation with the Director of the Office of Management and Budget, on the residential facility's expenditures, by category and source, during the base year and the fiscal year immediately preceding such base year.

(b) For purposes of this section, the term "base year" means the most recent fiscal year for which reliable fiscal data is available.

(c) The Secretary shall submit an annual report to the appropriate committees of the Congress summarizing (1) the number and types of residential facilities, by State, which have complied with the provisions of subsection (a) of this section and the data upon which such decisions were based, and (2) the number, types, and names of all residential facilities, by State, which have failed to comply with the provisions of subsection (a) of this section, the data upon which such decisions were based in each instance, and the steps which have been taken to withhold Federal assistance from such residential facilities.

WITHHOLDING OF GRANTS

SEC. 206. (a) After December 31, 1979, no residential facility or program of community care for individuals with developmental disabilities shall be eligible to receive payments either directly or indirectly under any Federal law, unless such residential facility meets the standards promulgated under parts C or D of this title or has demonstrated to the Secretary for a reasonable period of time that it has actively implemented the requirements of part B.

(b) The funds to which any individual would otherwise be entitled to have paid on his behalf to any ventor of residential services or program of community care, public or private, shall be reserved for him and administered by the Social Security Administration in the same manner as benefits under title II of the Social Security Act would be administered on his behalf were he entitled to same.

EVALUATION AND PERFORMANCE CRITERIA

SEC. 207. (a) The Secretary of Health, Education, and Welfare, in consultation with the Council established pursuant to section 202 of this title, shall develop and transmit to the appropriate committees of Congress within 18 months after the date of enactment an evaluation system and plan for implementation of such system designed to:

(1) assess the adequacy of all education and training, habilitation, rehabilitation, early childhood, diagnostic and evaluation services, or any other services or assistance under all laws administered by the Secretary; and

(2) develop specific criteria designed to provide objective measurement of the development progress of a developmentally disabled individual, which may be utilized by public agencies, residential facilities, and community based facilities and agencies to evaluate the effectiveness of the services provided to such individual.

(b) In developing such evaluation system the Secretary shall insure that such system is consumer oriented and is designed to—

(1) evaluate the effects of services on the lives of consumers, utilizing information and data obtained from individualized written habilitation plans as required under section 211,

(2) evaluate the overall impact of State and local programs for the developmentally disabled,

(3) provide and evaluate the cost-benefit ratios of particular service alternatives, and

(4) provide that evaluation of program quality shall be performed by individuals not directly involved in the delivery of such services to the program being evaluated.

(c) The Secretary, in consultation with the Council established pursuant to section 202, shall make grants and enter into contracts to conduct feasibility studies to assist in developing the evaluation system required under subsection (a) except that such grant or contract shall not be entered into with groups or individuals who are directly related to the program being evaluated.

(d) There are authorized to be appropriated to carry out the purposes of this section $1,000,000 each for the fiscal year ending June 30, 1975, and for the succeeding fiscal year.

PART B—ALTERNATIVE CRITERIA FOR COMPLIANCE IN LIEU OF STANDARDS FOR RESIDENTIAL AND COMMUNITY FACILITIES AND AGENCIES

PERFORMANCE CRITERIA

SEC. 210. (a) The Secretary shall specify detailed performance criteria for measuring and evaluating the developmental progress of a person with developmental disabilities who is receiving direct service in a residential or community based facility or agency and minimum compliance levels for such criteria which shall be applicable to residential and community facilities and agencies. Such performance criteria shall be developed pursuant to section 203 and shall be considered, along with minimum compliance levels, as required standards under this part.

(b) Prior to approving any compliance plan submitted under section 203, the Secretary shall obtain adequate assurance of compliance with the performance criteria developed under such section.

INDIVIDUALIZED WRITTEN HABILITATION PLAN

SEC. 211. (a) The Secretary shall insure that an individualized written habilitation plan is developed and modified at frequent intervals on behalf of each developmentally disabled person who is in a residential facility or community facility and agency for which standards have been established under this Act or under any other federally assisted State or local program specified by the Secretary.

(b) Each individualized written habilitation plan shall be developed jointly by a representative or representatives of the facility or agency primarily responsible for delivering or coordinating the delivery of services to the developmentally disabled person in a residential facility or community facility and agency and the developmentally disabled person (or, in appropriate cases, his parents or guardian). In any case in which such developmentally disabled person is receiving services from two or more distinct service agencies, the agency primarily responsible for delivering or coordinating the delivery of such services will also be responsible for insuring that all services are made part of the individualized written habilitation plan.

(c) Each individualized written habilitation plan shall be reviewed at least annually by the agency primarily responsible for delivery or coordinating the delivery of services referred to in subsection (b) at which time the developmentally disabled person (or, in appropriate cases, his parents or guardian) will be afforded an opportunity to review such plan and jointly redevelop its terms. Such plan shall include but not be limited to (1) a statement of long-term habilitation goals for the developmentally disabled person and intermediate habilitation objectives related to the attainment of such goals, (2) a statement of specific habilitation services to be provided, (3) the projected date for the initiation and the anticipated duration of each such service, and (4) objective criteria and an evaluation procedure and schedule for determining whether such objectives and goals are being achieved.

(d) Each individualized written habilitation plan shall conform to the following basic criteria:

(1) the initial plan shall be developed upon the person's application for service;

(2) such plan shall reflect the use of assessment data in at least the following areas:

(A) sensor-motor development;

(B) communicative development;

(C) social development;

(D) affective development; and

(E) cognitive development;

(3) the objectives of such plan shall be developed with the participation of:

(A) the person;

(B) the person's family or guardian;

(C) all relevant agency staff members; and

(D) staff of other agencies involved in serving the person;

(4) the objectives of such plan shall be—

(A) stated separately;

(B) stated in sequence with specific time periods; and

(C) expressed in behavioral terms that provide measurable indices of progress;

(5) such plan shall describe the conditions, activities, or barriers that interfere with the achievement of the objectives;

(6) such plan shall specify modes of intervention for the achievement of the stated objectives;

(7) such plan shall identify agencies which will deliver the services required;

(8) such plan shall identify a designated focus of responsibility for utilizing and coordinating services provided by different practitioners or agencies;

(9) such plan shall include a specification of proposed day-to-day training activities designed to assist in attaining the stated objectives;

(10) such plan shall be written in functional terms that are understandable to the person, and, as appropriate, his or her parents or guardians;

(11) such plan shall be reviewed at least quarterly in order to—

(A) measure the person's progress;

(B) modify the objectives of the plan as necessary;

(C) determine the services that are needed; and

(D) provide guidance and remediation techniques to modify barriers to growth; and

(12) such plan shall include a written agreement that specifies the role and objectives of each party to the implementation of the individualized written habilitation plan.

(e) The Secretary shall also insure that, in developing and carrying out each individualized written habilitation plan, primary emphasis will be given to placing the person in the least restrictive program and living environment commensurate with his capabilities and needs.

(f) The Secretary shall specify detailed performance criteria for measuring and evaluating the developmental progress of developmentally disabled persons attained through the use of such individualized written habilitation plans.

PROGRAM COORDINATION

SEC. 212. (a) Each person served by an agency shall be assigned by such agency a program coordinator responsible for implementing the person's individual written habilitation plan. The program coordinator's service to a person shall be terminated only when responsibility for service to the person has been effectively assumed by another agency, at which time a new program coordinator shall be assigned by the agency assuming responsibility.

(b) Each agency shall insure that—

(1) the person or his family shall participate in the selection of the program coordinator and the program coordinator shall be identified to the person, to his family, and to appropriate staff members;

(2) the program coordinator shall attend to the total spectrum of the person's needs, including, but not limited to, housing, family relationships, social activities, education, finances, employment, health, recreation, and records. In respect to these areas the program coordinator shall determine whether the person's needs are being met and how such needs are being met;

(3) the program coordinator shall provide supportive services to the person and his family;

(4) to keep the individual written habilitation plan up to date, the program coordinator shall secure relevant data from other agencies providing service;

(5) the program coordinator shall provide documentation relevant to the review of the individual written habilitation plan as required by section 211; and

(6) the program coordinator, or another agency staff member, shall assist the person, his or her family,

or his or her guardian, in planning for and securing living arrangements that are adapted to the person's needs.

PROTECTIVE AND PERSONAL ADVOCACY

SEC. 213. (a) The Secretary shall insure that a system of protective and personal advocacy is established in each State to monitor programs and services and protect the human and legal rights of each developmentally disabled person served by residential facilities or programs of community care within the State.

(b) The Secretary shall insure that for each such system an agency or entity is designated which (1) is independent of any agency providing services directly or indirectly, (2) is capable of providing protective and personal advocacy services, and (3) shall be responsible for monitoring and auditing the individualized programs of persons to insure that they receive all of the benefits, services, and rights to which they are entitled under any law or program thereunder.

(c) (1) Such system shall include the establishment of an independent entity which has the authority to receive all complaints regarding the infringement of rights, or denial of benefits, or the failure to provide services necessary to assure the human and legal rights of all developmentally disabled persons within the State.

(2) Each entity established pursuant to paragraph (1) shall be empowered to render a decision with respect to any complaint, including an order to provide services or such other remedy which may be deemed appropriate, and such decision shall be final and binding. Prior to the issuance of any order or decision rendered pursuant to this paragraph, any party which may be affected by such order or decision may request a hearing, which shall be held within 60 days after a complaint is received, and such order or decision shall be rendered within 60 days after such hearing is concluded. Such order or decision shall be subject to appropriate judicial review.

RECORD REQUIREMENTS

SEC. 214. (a) The residential and community facilities and agencies shall keep such records as the Secretary or the State may deem appropriate to evaluate the effectiveness of performance and compliance with the provisions of this part.

(b) Each residential and community facility and agency shall identify the number of developmentally disabled persons rejected for services by such facility or agency, and the reasons for each such rejection, and report such information every 6 months to the Secretary and the State.

MINIMUM STANDARDS FOR USE WITH THE ALTERNATE PROCEDURE

SEC. 215. Each residential and community facility and agency desiring to use the alternative procedures of this part in lieu of compliance with parts C and D of this title shall insure—

(1) that close relatives shall be permitted to visit a person at any reasonable hour and without prior notice: *Provided*, That the privacy and rights of the other residents and person are not infringed thereby;

(2) the implementation of advocacy for all residents and persons;

(3) that no individual whose needs cannot be met by the residential facility or agency shall be admitted to it;

(4) that the number of persons admitted as residents or persons to the residential facility or agency shall not exceed—

(A) its rated capacity; and

(B) its provisions for adequate programing;

(5) that there is a regular, at least annual, joint review of the status of each resident or person by all relevant personnel, including personnel in the living unit with program recommendations for implementation, to include—

(A) consideration of the advisability of continued residence and alternative programs, and

(B) at the time of the resident's or person's attained majority, or if he becomes emancipated prior thereto:

(i) the resident's or person's need for remaining in the residential facility;

(ii) the need for guardianship of the resident or person; and

(iii) the protection of the resident's or person's civil and legal rights;

(6) that mistreatment of residents and persons shall be strictly prohibited, that any such mistreatment shall be reported immediately by the facility or agency to the State, that—

(A) all alleged incidents of mistreatment thoroughly investigated;

(B) the results of such investigation are reported to the chief executive officer, or his designated representative, within 24 hours of the incident; and

(C) appropriate sanctions are invoked when the allegations of mistreatment are substantiated;

(7) that living unit personnel shall train residents and persons in activities of daily living and in the development of self-help and social skills;

(8) that living unit personnel shall be responsible for the development and maintenance of a warm, family or home like environment that is conducive to the

achievement of optimal development by the resident or person;

(9) that the rhythm of life in the living unit shall resemble the cultural norm of the resident's or person's nonretarded or nondevelopmentally disabled age peers, unless a departure from this rhythm is justified on the basis of maximizing the resident's or person's human qualities;

(10) that residents and persons shall be assigned responsibilities in the living unit commensurate with their interests, abilities, and developmental plans, in order to enhance feelings of self-respect and to develop skills of independent living, and that multiple-handicapped and nonambulatory residents or persons shall—

(A) spend a major portion of their waking day out of bed;

(B) spend a portion of their waking day out of their bedroom areas; and

(C) have planned daily activity and exercise periods;

(11) that residents and persons shall be provided with systematic training to develop appropriate eating skills utilizing adaptive equipment where it serves the developmental process;

(12) that, in accordance with the normalization principle, all professional services to mentally retarded and other persons with developmental disabilities shall, to the extent feasible, be provided in the community, rather than in a residential facility, and where provided in a residential facility, such services must be at least comparable to those provided in the community;

(13) that educational services (defined as deliberate attempts to facilitate the intellectual sensorimotor and effective development of the individual) shall be available to all residents and persons regardless of chronological age, degree of retardation, or accompanying disabilities or handicaps, and for residents or persons of legal school age the State shall insure that the State educational agency provides educational services equivalent to those provided to the nonhandicapped population; and

(14) that special attention shall be given those residents and persons, without active intervention, are at the risk of further loss of function, including—

(A) early diagnosis of disease;

(B) prompt treatment in the early stages of disease;

(C) limitation of disability by arresting the disease process;

(D) prevention of complications and sequelae; and

(E) rehabilitation services to raise the resident or person to his greatest possible level of function in spite of his or her handicap, by maximizing the use of his or her existing capabilities;

(15) that the civil rights of all residents are assured;

(16) that no physical restraint shall be employed unless absolutely necessary. Restraint shall not be used as punishment or substitute for program, and a written policy available to the public shall govern any use of restraint. Orders for restraint shall not be in force for periods of longer than twelve hours. Residents placed in restraint shall be checked at least every thirty minutes by trained staff. Mechanical restraints shall be designed to insure the least discomfort. Opportunity for motion and exercise shall be provided for not less than fifteen minutes during each two hours when restraint is employed. Totally enclosed cribs and barred enclosures shall be considered restraints;

(17) that chemical restraint shall not be used excessively, or as punishment or substitute for program or in quantities that inferfere with habilitation programs;

(18) that a nourishing, well-balanced diet shall be provided all residents;

(19) that medical and dental services shall be provided to all residents and shall include—

(a) preventive health services;

(b) evaluation, diagnosis, consultation, and treatment; and

(c) infections and contagious disease control;

(20) that adequate fire and safety standards as promulgated in regulations by the Secretary shall be met, and such standards shall include—

(a) adequate and alternate exits and exit doors;

(b) exit ramps with nonskid surfaces and slopes not to exceed one foot in twelve;

(c) handrails on stairways;

(d) unencumbered aisles and exits and uncluttered floors; and

(e) proper storage and other adequate safeguards for flammable materials;

(21) that paint used in facilities shall be lead free; and

(22) that there shall be adequate sanitation and waste disposal procedures to protect the health of the residents.

PART C—STANDARDS FOR RESIDENTIAL FACILITIES FOR MENTALLY RETARDED AND OTHER PERSONS WITH DEVELOPMENTAL DISABILITIES

Chapter 1.—ADMINISTRATIVE POLICIES AND PRACTICES

Subchapter I—Philosophy, Location, and Organization

SEC. 220. (a) The ultimate aim of the residential facility shall be to foster those behaviors that maximize the human qualities of the resident, increase the complexity of his or her behavior, and enhance his or her ability to cope with his or her environment.

(b) The residential facility shall accept and implement the principle of normalization defined as the use of means that are as culturally normative as possible to elicit and maintain behavior that is culturally normative as possible, taking into account local and subcultural differences.

(c) The names of residential facilities, the labels applied to their users, and the way these users are interpreted to the public should be appropriate to their purposes and programs and services should not emphasize "mental retardation" or "deviancy".

(d) Residents should not be referred to as "patient" except in a hospital-medical context; as "kids" or "children" if they are adults; or as "inmates"; or as "clients".

SEC. 221. (a) The residential facility should be located within, and conveniently accessible to, the population served, so as to have access to necessary generic community services.

(b) The residential facility should not be isolated from society or community by factors such as:

(1) difficulty of access, due to distance or lack of public transportation;

(2) architectural features;

(3) sociocultural or psychological features; and

(4) rules, regulations, customs, and habits.

(c) Protection devices (such as fences and security windows), where necessary, should be inconspicuous, and should preserve as normal an environmental appearance as possible, so as to permit the pursuit of normal activities.

(d) The residential facility should be in scale with the community in which it is located.

(e) The residential facility and the surrounding community should be encouraged to share their services and resources on a reciprocal basis.

(f) The community in which the residential facility is located should be capable of meeting the needs of the residential facility's residents for generic and specialized services.

(g) The community in which the residential facility is located should be capable of absorbing, and encouraged to absorb, into its cultural life those residents capable of participation in that life.

(h) The residential facility shall have available a current descriptive directory of community resources.

Sec. 222. (a) Residents should be integrated to the greatest possible extent with the general population. To this end, generic and specialized community services, rather than residential facility services, should be used extensively or, if possible, completely. The residents should, including but not limited to—

(1) attend (special) classes or programs in regular schools;

(2) attend religious instruction and worship in the community;

(3) utilize medical, dental, and all other professional services located in the community;

(4) use community rather than residential facility recreation resources, such as bowling alleys, swimming pools, movies, and gymnasia;

(5) shop in community stores, rather than in industrial facility stores and canteens; and

(6) work in as integrated a fashion as possible and sheltered employment should be in regular industry, and among nonretarded workers; sheltered workshops should be in the community; and work that must be on

the campus of the industrial facility should afford maximal contact with nonretarded persons.

There shall be evidence of professional and public education to facilitate the integration of residents, as above set forth.

(b) The residential facility should be divided into groupings of program and residence units, based upon a rational plan to meet the needs of the residents and fulfill the purposes of the residential facility.

SEC. 223. The residential facility shall to the maximum extent feasible move residents from—

(1) more to less structured living;

(2) larger to smaller residential facilities;

(3) larger living units to smaller living units;

(4) group to individual residence;

(5) dependent to independent living; and

(6) segregated to integrated living.

Subchapter II—General Policies and Practices

SEC. 224. (a) The residential facility shall have a written outline of the philosophy, objectives, and goals it is striving to achieve, that is available for distribution to staff, consumer representatives, and the interested public, and that shall include but need not be limited to:

(1) its role in the State comprehensive program for the mentally retarded and other individuals with developmental disabilities;

(2) its concept of the rights of its residents;

(3) its goals for its residents;

(4) its concept of its relationship to the parents of its residents, or to their surrogates;

(5) its concept of its relationship to the community, zone, or region from which its residents come;

(6) its concept of its responsibility (through research, training, and education) for improving methods, understanding, and support for the mental retardation and developmentally disabled field.

(b) The residential facility shall have a plan for evaluation and modification to maintain:

(1) the consistency of its philosophy, objectives, and goals with advancements in knowledge and professional practices; and

(2) the consistency of its practices with its philosophy, objectives, and goals.

(c) The residential facility shall have a manual on policies and procedures, describing the current methods, forms, processes, and sequence of events being followed to achieve its objectives and goals.

(d) The residential facility shall have a written statement of policies and procedures concerning the rights of residents that—

(1) assure the civil rights of all residents;

(2) are in accordance with general and special rights of the mentally retarded and other individuals with developmental disabilities as defined by the Secretary in accordance with section 201 of this title; and

(3) define the means of making legal counsel available to residents for the protection of their rights.

SEC. 225. (a) The residential facility shall have a written statement of policies and procedures that protect the financial interests of residents and that provided for—

(1) determining the financial benefits for which the resident is eligible;

(2) assuring that the resident receives the funds for incidentals and for special needs (such as specialized equipment) that are due him or her under public and private financial support programs; and

(3) when large sums accrue to the resident, providing for counseling of the resident concerning their use, and for appropriate protection of such funds.

(b) Procedures in the major operating units of the residential facility shall be described in manuals that are current, relevant, available, and followed.

(c) The residential facility shall have a summary of the laws and regulations relevant to mental retardation and other developmental disabilities and to the function of the residential facility.

(d) The residential facility shall have a plan for a continuing management audit to insure compliance with State laws and regulations and the effective implementation of its stated policies and procedures.

SEC. 226. (a) A public residential facility shall have documents that describe the statutory basis of its existence, and describe the administrative framework of the governmental department in which it operates.

(b) A private residential facility shall have documents that include its charter, its constitution and bylaws, and its State license.

SEC. 227. (a) The governing body of the residential facility shall exercise general direction and shall establish policies concerning the operation of the residential facility and the welfare of the individuals served.

(b) The governing body shall establish appropriate qualifications of education, experience, personal factors, and skills for the chief executive officer. The chief executive officer shall have had training and experience in the administration of human services. The chief executive officer shall have administrative ability, leadership ability, and an understanding of mental retardation and other developmental disabilities. Where the chief executive officer is required also to have had training in a professional service discipline, such training shall be in a discipline appropriate to the residential facility's program.

(c) The governing body shall employ a chief executive officer so qualified, and shall delegate to him or her authority and responsibility for the management of the affairs of the residential facility in accordance with established policies.

(d) The chief executive officer shall—

(1) designate an individual to act for him or her in his or her absence;

(2) make arrangements so that some one individual is responsible for the administrative direction of the residential facility at all times;

(3) when an assistant chief executive officer is employed, the qualifications required for this position shall be in compliance with those stated above for the chief executive officer; and

(4) there shall be on the premises of the residential facility at all times a person designated by the chief executive officer, or the person acting for him or her, to be responsible for the supervision of the residential facility.

SEC. 228. (a) The residential facility shall be administered and operated in accordance with sound management principles.

(b) The type of administrative organization of the residential facility shall be appropriate to the program needs of its residents.

(c) The residential facility shall have a table of organization that shows the governance and administrative pattern of the residential facility.

(d) The table of organization shall show the major operating programs of the residential facility, with staff divisions, the administrative personnel in charge of the programs and divisions, and their lines of authority, responsibility, and communication.

(e) The organization shall provide for the judicious delegation of administrative authority and responsibility among qualified members of the staff, in order to distribute the administrative load of the residential facility and to accelerate its operating efficiency.

(f) The organization shall be such that problems requiring ongoing decisionmaking regarding the welfare of the resident are handled primarily by personnel on the lowest level competent to resolve the problem.

(g) The organization shall provide for the utilization of staff with different levels of training by using those with more adequate training to supervise and train those with lesser training.

(h) The organization shall provide effective channels of communication in all directions.

(i) The residential facility shall have a plan for improving the quality of staff and services that shows how the staff functions by programmatic responsibilities in establishing and maintaining standards of quality for services to residents. The plan shall show how the residential facility's organizational structure enables the following functions:

(1) determination of standards for quality of services to the residents;

(2) establishment of qualifications for personnel;

(3) recruitment of qualified personnel;

(4) initiation of preservice and inservice training and staff development programs;

(5) work with administrators, supervisors, and staff of the administrative units of the residential facility to secure and assign qualified personnel to such units;

(6) annual evaluation of staff performance;

(7) continuous evaluation of program effectiveness; and

(8) development and conduct of appropriate research activities.

SEC. 229. (a) The administration of the residential facility shall provide for effective staff and resident participation and communication. Staff meetings shall be regularly held. Standing committees appropriate to the residential facility, such as records, safety, human rights, utilization review, research review, and infection and sanitation, shall meet regularly. Committees shall include resident participation, whenever appropriate. Committees shall include the participation of direct-care staff, whenever appropriate.

(b) Minutes and reports of staff meetings, and of standing and ad hoc committee meetings shall include records of recommendations and their implementation, and shall be kept and filed. Summaries of the minutes and reports of staff and committee meetings shall be distributed to participants and to appropriate staff members. Various forms of communication (such as meetings, minutes of meetings, directives, and bulletins) shall be utilized to foster understanding among the staff, among the residents, between staff and residents, and between residential facility, community, and family.

SEC. 230. (a) The facility shall designate a percentage of its operating budget for self-renewal purposes, including but not limited to:

(1) development of operational data records;

(2) research on its own programs;

(3) evaluation by qualified persons who are not part of the residential facility;

(4) elicitation of feedback from consumers of the residential facility's services, or from their representatives; and

(5) staff education.

(b) The findings generated by the foregoing activities shall be actively and broadly disseminated to:

(1) all members of the residential facility's staff; and

(2) consumer representatives, when appropriate.

(c) The residential facility shall have a continuing system for collecting and recording accurate data that describe its population, in such form as to permit data retrieval and usage for description, programing of services, and research. Such data shall include, but need not be limited to:

(1) number by age-groups, sex, and race;

(2) number grouped by levels of retardation (profound, severe, moderate, mild, and borderline), according to the appropriate nationally recognized professional association on mental deficiency's manual on terminology and classification in mental retardation;

(3) number grouped by levels of adaptive behavior, according to the appropriate nationally recognized professional association on mental deficiency classification;

(4) number with physical disabilities;

(5) number ambulatory and nonambulatory (mobile and nonmobile);

(6) number with sensory defects;

(7) number with oral and other communication handicaps; and

(8) number with convulsive disorders, grouped by level of seizure control.

SEC. 231. The residential facility shall have a description of services for residents that is available to the public and that includes information including but not limited to:

(1) groups served;

(2) limitations concerning age, length of residence, or type or degree of handicap;

(3) the plan for grouping residents into program and living units;

(4) preadmission and admission services;

(5) diagnosis and evaluation services;

(6) means for individual programing of residents in accordance with need;

(7) means for implementation of programs for residents, through clearly designated responsibility;

(8) the therapeutic and developmental environment provided the residents; and

(9) release and follow-up services and procedures.

SEC. 232. (a) The residential facility shall provide for meaningful and extensive consumer-representative and public participation, by the following means:

(1) the policymaking or governing board (if any) shall include consumers or their representatives (for example, parents), interested citizens, and relevantly qualified professionals presumed to be free of conflicts of interest;

(2) when a residential facility does not have a governing board, its policymaking authority shall actively seek advice from an advisory body composed as described above;

(3) the residential facility shall actively elicit feedback from those consumers of its services (and their representatives) who are not members of the aforementioned governing or advisory bodies;

(4) there shall be an active program of ready, open, and honest communication with the public. In structuring visits to the residential facility by persons not directly concerned with a resident, however, steps shall be taken both to encourage visiting and to consider the sensibilities and privacy of the residents. Undignified displays or exhibitions of residents shall be avoided, and normal sensibility shall be exercised in speaking about a resident;

(5) personnel shall be permitted to communicate their views about a resident and his needs and program

to his relatives. Personnel shall be trained to properly and competently assume this responsibility;

(6) the residential facility shall maintain active means of keeping residents' families or surrogates informed of activities related to the residents that may be of interest to them;

(7) communications to the residential facility from residents' relatives shall be promptly and appropriately handled and answered;

(8) close relatives shall be permitted to visit at any reasonable hour, and without prior notice. Steps shall be taken, however, so that the privacy and rights of the other residents are not infringed by this practice;

(9) parents and other visitors shall be encouraged to visit the living units, with due regard for privacy. There shall be residential facilities for visiting that provide privacy in the living unit (but not special rooms used solely for visiting);

(10) parents shall be permitted to visit all parts of the residential facility that provide services to residents;

(11) frequent and informal visits home shall be encouraged, and the regulations of the residential facility shall encourage rather than inhibit such visitations;

(12) there shall be an active citizens' volunteer program; and

(13) the residential facility shall acknowledge the need for, and encourage the implementation of, advocacy for all residents.

(b) A public education and information program should be established that utilizes all communication media, and all service, religious, and civic groups, and so forth, to develop attitudes of understanding and acceptance of the mentally retarded and other individuals with developmental disabilities in all aspects of community living.

Subchapter III—Admission and Release

SEC. 233. No individual whose needs cannot be met by the residential facility shall be admitted to it. The number admitted as residents to the residential facility shall not exceed—

(1) its rated capacity; and

(2) its provisions for adequate programing.

SEC. 234. (a) The laws, regulations, and procedures concerning admission, readmission, and release shall be summarized and available for distribution. Admission and release procedures shall—

(1) encourage voluntary admission, upon application of parent or guardian or self;

(2) give equal priority to persons of comparable need, whether application is voluntary or by a court;

(3) facilitate emergency, partial, and short-term residential care, where feasible; and

(4) utilize the maximum feasible amount of voluntariness in each individual case.

(b) The determination of legal incompetence shall be separate from the determination of the need for residential services, and admission to the residential facility shall not automatically imply legal incompetence.

SEC. 235. (a) The residential facility shall admit only residents who have had a comprehensive evaluation, covering physical, emotional, social, and cognitive factors, conducted by an appropriately constituted interdisciplinary team.

(b) Initially, service need shall be defined without regard to the actual availability of the desirable options. All available and applicable programs of care, treatment, and training shall be investigated and weighed, and the deliberations and findings recorded. Admission to the residential facility shall occur only when it is determined to be the optimal available plan. Where admission is not the optimal measure, but must nevertheless be recommended or implemented, its inappropriateness shall be clearly acknowledged and plans shall be initiated for the continued and active exploration of alternatives.

(c) The intended primary beneficiary of the admission shall be clearly specified as—

(1) the resident;

(2) his or her family;

(3) his or her community;

(4) society; and

(5) any combination of the above.

(d) All admissions to the residential facility shall be considered temporary, and, when appropriate, admissions shall be time limited. Parents or guardians shall be counseled, prior to admission, on the relative advantages and disadvantages and the temporary nature of residential services in the residential facility. Prior to admission, parents or guardians shall, and the prospective resident should, have visited the residential facility and the living unit in which the prospective resident is likely to be placed.

SEC. 236. (a) A medical evaluation by a licensed physician shall be made within one week of the resident's admission. Upon admission, residents should be placed in their program groups, and they should be isolated only upon medical orders issued for specific reasons.

(b) Within the period of 1 month after admission there shall be:

(1) a review and updating of the preadmission evaluation;

(2) a prognosis that can be used for programing and placement;

(3) a comprehensive evaluation and individual program plan, made by an interdisciplinary team;

(4) direct-care personnel shall participate in the aforementioned activities;

(5) the results of the evaluation shall be recorded in the resident's unit record;

(6) an interpretation of the evaluation, in action terms, shall be made to:

(A) the direct-care personnel responsible for carrying out the resident's program;

(B) the special services staff responsible for carrying out the resident's program; and

(C) the resident's parents or their surrogates.

(c) There shall be a regular, at least annual, joint review of the status of each resident by all relevant personnel, including personnel in the living unit, with program recommendations for implementation. This review shall include—

(1) consideration of the advisability of continued residence and alternative programs;

(2) at the time of the resident's attaining majority, or if he becomes emancipated prior thereto:

(A) the resident's need for remaining in the residential facility;

(B) the need for guardianship of the resident;

(C) the exercise of the resident's civil and legal rights;

(3) The results of these reviews shall be:

(A) recorded in the resident's unit record;

(B) made available to relevant personnel;

(C) interpreted to the resident's parents or surrogates;

(D) interpreted to the resident, when appropriate; and

(4) parents or their surrogates shall be involved in planning and decisionmaking.

SEC. 237. A physical inspection for signs of injury or disease should be made in accordance with procedures established by the residential facility:

(A) within 24 hours prior to a resident's leaving residential facility for vacation, placement, or other temporary or permanent release; and

(B) within 24 hours following a resident's return to the residential facility from such absence.

SEC. 238. (a) At the time of permanent release or transfer, there shall be recorded a summary of findings, progress, and plans.

(b) Planning for release shall include provision for appropriate services, including protective supervision and other followup services, in the resident's new environment. Procedures shall be established so that—

(1) parents or guardians who request the release of a resident are counseled concerning the advantages and disadvantages of such release; and

(2) the court or other appropriate authorities are notified when a resident's release might endanger either the individual or society.

(c) When a resident is transferred to another residential facility there shall be—

(1) written evidence that the reason for the transfer is the welfare of the resident; and

(2) a transfer process that shall insure that the receiving residential facility will meet the needs of the resident.

(d) Except in an emergency, transfer shall be made only with the prior knowledge, and ordinarily the consent, of the resident and his or her guardian.

SEC. 239. (a) In the event of any unusual occurrence, including serious illness or accidents, impending death, or death, the resident's next of kin, or the person who functions in that capacity (a guardian or citizen advocate) shall be notified promptly and in a compassionate manner. When appropriate, the wishes and needs of the resident, and of the next of kin, concerning religious matters shall be determined and, insofar as possible, fulfilled.

(b) When death occurs:

(1) with the permission of the next of kin or legal guardian, an autopsy shall be performed;

(2) such autopsy shall be performed by a qualified physician, so selected as to be free of any conflict of interest or loyalty;

(3) the family shall be told of the autopsy findings, if they so desire; and

(4) the residential facility shall render as much assistance as possible in making arrangements for dignified religious services and burial, unless contraindicated by the wishes of the family.

(c) The coroner or medical examiner shall be notified of deaths, in accordance with State law.

Subchapter IV—Personnel Policies

SEC. 240. (a) Adequate personnel services shall be provided by means appropriate to the size of the residential facility. If the size of the residential facility warrants a personnel director, he shall have had several years of progressively more responsible experience or training in personnel administration, and demonstrated competence in this area.

(b) The residential facility's current personnel policies and practices shall be described in writing:

(1) The hiring, assignment, and promotion of employees shall be based on their qualifications and abilities, without regard to sex, race, color, creed, age, irrelevant disability, marital status, ethnic or national origin, or membership in an organization.

(2) Written job descriptions shall be available for all positions.

(3) Licensure, certification, or standards such as are required in community practice shall be required for all comparable positions in the residential facility.

(4) Ethical standards of professional conduct, as developed by appropriate professional societies, shall be recognized as applying in the residential facility.

(5) There shall be a planned program for career development and advancement for all categories of personnel.

(6) There shall be an authorized procedure, consistent with due process, for suspension or dismissal of an employee for cause.

(7) Methods of improving the welfare and security of employees shall include:

(A) a merit system or its equivalent;

(B) a salary schedule covering all positions;

(C) effective grievance procedures;

(D) provisions for vacations, holidays, and sick leave;

(E) provisions for health insurance and retirement;

(F) provisions for employee organizations;

(G) opportunities for continuing educational experiences, including educational leave; and

(H) provisions for recognizing outstanding contributions to the residential facility.

(c) A statement of the residential facility's personnel policies and practices shall be available to all its employees.

(d) All personnel shall be initially screened to determine if they are capable of fulfilling the specific job requirements. All personnel shall be medically determined to be free of communicable and infectious diseases at the time of employment and annually thereafter. All personnel should have a medical examination at the time of employment and annually thereafter. Where indicated, psychological assessment should be included at the time of employment and annually thereafter.

(e) The performance of each employee shall be evaluated regularly and periodically, and at least annually. Each such evaluation shall be—

(1) reviewed with the employee; and

(2) recorded in the employee's personnel record.

(f) Written policy shall prohibit mistreatment, neglect, or abuse of residents. Alleged violations shall be reported immediately, and there shall be evidence that—

(1) all alleged violations are thoroughly investigated;

(2) the results of such investigation are reported to the chief executive officer, or his or her designated representative, within 24 hours of the report of the incident; and

(3) appropriate sanctions are invoked when the allegation is substantiated.

SEC. 241. (a) Staffiing shall be sufficient so that the residential facility is not dependent upon the use of residents or volunteers for productive services. There shall be a written policy to protect residents from exploitation when they are engaged in productive work. A current, written policy shall encourage that residents be trained for productive, paid employment. Residents shall not be involved in the care (feeding, clothing, bathing), training, or supervision of other residents unless they—

(1) have been specifically trained in the necessary skills;

(2) have the humane judgment required by these activities;

(3) are adequately supervised; and

(4) are reimbursed.

(b) Residents who function at the level of staff in occupational or training activities shall—

(1) have the right to enjoy the same privileges as staff; and

(2) be paid at the legally required wage level when employed in other than training situations.

(c) Appropriate to the size and nature of the residential facility, there shall be a staff training program that includes:

(1) orientation for all new employees, to acquaint them with the philosophy, organization, program, practices, and goals of the residential facility;

(2) induction training for each new employee, so that his skills in working with the residents are increased;

(3) inservice training for employees who have not achieved the desired level of competence, and opportunities for continuous inservice training to update and improve the skills and competencies of all employees;

(4) supervisory and management training for all employees in, or candidates for, supervisory positions;

(5) provisions shall be made for all staff members to improve their competencies, through means, including but not limited to—

(A) attending staff meetings;

(B) undertaking seminars, conferences, workshops, and institutes;

(C) attending college and university courses;

(D) visiting other residential facilities;

(E) participation in professional organizations;

(F) conducting research;

(G) publishing studies;

(H) access to consultants;

(I) access to current literature, including books, monographs, and journals relevant to mental retardation and developmental disabilities;

(6) interdisciplinary training programs shall be stressed;

(7) the ongoing staff development program should include provisions for educating staff members as research consumers;

(8) where appropriate to the size and nature of the residential facility, there shall be an individual designated to be responsible for staff development and training, and such individual should have—

(A) at least a master's degree in one of the major disciplines relevant to mental retardation or other developmental disability;

(B) a thorough knowledge of the nature of mental retardation and other developmental disabilities, and the current goals, programs, and practices in this field;

(C) a knowledge of the educational process;

(D) an appropriate combination of academic training and relevant experience;

(E) demonstrated competence in organizing and directing staff training programs; and

(9) appropriate to the size and nature of the residential facility, there should be adequate, modern educational media equipment (including but not limited to: overhead, filmstrip, motion picture, and slide projectors; screens; models and charts; and video tape systems) for the conduct of an inservice training program.

(d) Working relations should be established between the residential facility and nearby colleges and universities for the following purposes:

(1) making credit courses, seminars, and workshops available to the residential facility's staff;

(2) using residential facility resources for training and research by colleges and universities; and

(3) exchanging of staff between the residential facility and the colleges and universities for teaching, research, and consultation.

Chapter 2.—RESIDENT LIVING

Subchapter I—Staff-Resident Relationships and Activities

SEC. 242. (a) The primary responsibility of the living unit staff shall be to devote their attention to the care and development of the residents as follows:

(1) each resident shall receive appreciable and appropriate attention each day from the staff in the living unit;

(2) living unit personnel shall train residents in activities of daily living and in the development of self-help and social skills;

(3) living unit personnel shall be responsible for the development and maintenance of a warm, family- or home-like environment that is conducive to the achievement of optimal development by the resident;

(4) appropriate provision shall be made to ensure that the efforts of the staff are not diverted from these responsibilities by excessive housekeeping and clerical duties, or other non-resident-care activities; and

(5) the objective in staffing each living unit should be to maintain reasonable stability in the assignment of staff, thereby permitting the development of a consistent inter-personal relationship between each resident and one or two staff members.

(b) Members of the living unit staff from all shifts shall participate with an interdisciplinary team in appropriate referral, planning, initiation, coordination, implementation, followthrough, monitoring, and evaluation activities relative to the care and development of the resident.

(c) There shall be specific evaluation and program plans for each resident that are—

(1) available to direct care staff in each living unit; and

(2) reviewed by a member or members of the interdisciplinary program team at least monthly, with documentation of such review entered in the resident's record.

(d) Activity schedules for each resident shall be available to direct care staff and shall be implemented daily as follows:

(1) such schedules shall not permit "dead time" of unscheduled activity of more than 1 hour continuous duration; and

(2) such schedules shall allow for individual or group free activities, with appropriate materials, as specified by the program team.

(e) The rhythm of life in the living unit shall resemble the cultural norm for the residents' nonretarded or nondevelopmentally disabled age peers, unless a departure from this rhythm is justified on the basis of maximizing the residents' human qualities. Residents shall be assigned responsibilities in the living unit commensurate with their interests, abilities, and developmental plans, in order to enhance feelings of self-respect and to develop skills of independent living. Multiple-handicapped and nonambulatory residents shall—

(1) spend a major portion of their waking day out of bed;

(2) spend a portion of their waking day out of their bedroom area;

(3) have planned daily activity and exercise periods; and

(4) be rendered mobile by various methods and devices.

(f) All residents shall have planned periods out of doors on a year-round basis. Residents should be instructed in how to use, and, except as contraindicated for individual residents by their program plan, should be given opportunity for freedom of movement—

(1) within the residential facility's ground; and

(2) without the residential facility's grounds.

Birthdays and special events should be individually observed. Provisions shall be made for heterosexual interaction appropriate to the residents' developmental levels.

(g) Residents' views and opinions on matters concerning them should be elicited and given consideration in defining the processes and structures that affect them.

(h) Residents should be instructed in the free and unsupervised use of communication processes. Except as denied individual residents by team action, for cause, this should typically include—

(1) having access to telephones for incoming and local outgoing calls;

(2) having free access to pay telephones, or the equivalent, for outgoing long distance calls;

(3) opening their own mail and packages, and generally doing so without direct surveillance; and

(4) not having their outgoing mail read by staff, unless requested by the resident.

(i) Residents shall be permitted personal possessions, such as toys, books, pictures, games, radios, arts and crafts materials, religious articles, toiletries, jewelry and letters.

(j) Regulations shall permit normalized and normalizing possession and use of money by residents for work payment and property administration as for example, in performing cash and check transactions, and in buying clothing and other items, as readily as other citizens. In accordance with their developmental level—

(1) allowances or opportunities to earn money shall be available to residents; and

(2) residents shall be trained in the value and use of money.

(k) There shall be provision for prompt recognition and appropriate management of behavioral problems in the living unit. There shall be a written statement of policies and procedures for the control and discipline of residents that is—

(1) directed to the goal of maximizing the growth and development of the residents;

(2) available in each living unit; and

(3) available to parents or guardians.

(l) Residents shall participate, as appropriate, in the formulation of such policies and procedures. Corporal punishment shall not be permitted. Residents shall not discipline other residents, except as part of an organized self-government program that is conducted in accordance with written policy.

(m) Seclusion, defined as the placement of a resident alone in a locked room, shall not be employed.

(n) Except as provided in subsection (p), physical restraint shall be employed only when absolutely necessary to protect the resident from injury to himself and to others, and restraint shall not be employed as punishment, for the convenience of staff, or as a substitute for program. The residential facility shall have a written policy that defines the uses of restraint, the staff members who may authorize its use, and a mechanism for monitoring and controlling its use. Orders for restraints shall not be in force for longer than 12 hours. A resident placed in restraint shall be checked at least every 30 minutes by staff trained in the use of restraints, and a record of such checks shall be kept. Mechanical restraints shall be designed and used so as not to cause physical injury to the resident, and so as to cause the least possible discomfort. Opportunity for motion and exercise shall be provided for a period of not less than 10 minutes during each 2 hours in which restraint is employed. Totally enclosed cribs and barred enclosures shall be considered restraints.

(o) Mechanical supports used in normative situations to achieve proper body position and balance shall not be considered to be restraints, but shall be designed and applied—

(1) under the supervision of a qualified professional person; and

(2) so as to reflect concern for principles of good body alinement, concern for circulation, and allowance for change of position.

(p) Chemical restraint shall not be used excessively, as punishment, for the convenience of staff, as a substitute for program, or in quantities that interfere with a resident's habilitation program.

(q) Behavior modification programs involving the use of time-out devices or the use of noxious or aversive stimuli shall be:

(1) reviewed and approved by the residential facility's research review and human rights committees;

(2) conducted only with the consent of the affected resident's parents or surrogates;

(3) described in written plans that are kept on file in the residential facility;

(4) restraints employed as time-out devices shall be applied for only very brief periods, only during conditioning sessions, and only in the presence of the trainer; and

(5) removal from a situation for time-out purposes shall not be for more than 1 hour, and this procedure shall be used only during the conditioning program, and only under the supervision of the trainer.

Subchapter II—Food Services

SEC. 243. (a) Food services shall recognize and provide for the physiological, emotional, religious, and cultural needs of each resident, through provision of a planned, nutritionally adequate diet. There shall be a written statement of goals, policies, and procedures that—

(1) governs all food service and nutrition activities;

(2) is prepared by, or with the assistance of, a nutritionist or dietitian;

(3) is reviewed periodically, as necessary, by the nutritionist or dietitian;

(4) is in compliance with State and local regulations;

(5) is consistent with the residential facility's goals and policies; and

(6) is distributed to residential facility personnel.

(b) When food services are not directed by a nutritionist or dietitian, regular, planned, and frequent consultation with a nutritionist or dietitian should be available. Records of consultations and recommendations shall be maintained by the residential facility and by the consultant. An evaluation procedure shall be established to determine the extent of implementation of the consultant's recommendations.

(c) A nourishing, well-balanced diet, consistent with local customs, shall be provided all residents. Modified diets shall be—

(1) prescribed by the resident's program team, with a record of the prescription kept on file;

(2) planned, prepared, and served by persons who have received adequate instruction; and

(3) periodically reviewed and adjusted as needed.

(d) Dietary practices in keeping with the religious requirements of residents' faith groups should be observed at the request of parents or guardians. Denial of a nutritionally adequate diet shall not be used as a punishment. At least three meals shall be served daily, at regular times, with—

(1) not more than a 14-hour span between a substantial evening meal and breakfast of the following day, and

(2) not less than 10 hours between breakfast and the evening meal of the same day.

(e) Resident's mealtimes shall be comparable to those normally obtaining in the community. Provision should be made for between meal and before bedtime snacks, in keeping with the total daily needs of each resident. Food shall be served—

(1) as soon as possible after preparation, in order to conserve nutritive value;

(2) in an attractive manner;

(3) in appropriate quantity;

(4) at appropriate temperature;

(5) in a form consistent with the developmental level of the resident; and

(6) with appropriate utensils.

When food is transported, it shall be done in a manner that maintains proper temperature, protects the food from contamination and spoilage, and insures the preservation of nutritive value.

(f) All residents, including the mobile nonambulatory, shall eat or be fed in dining rooms, except where contraindicated for health reasons, or by decision of the team responsible for the resident's program. Table service shall be provided for all who can and will eat at a table, including residents in wheelchairs. Dining areas shall—

(1) be equipped with tables having smooth, impervious tops or clean table coverings may be used;

(2) be equipped with tables, chairs, eating utensils, and dishes designed to meet the developmental needs of each resident;

(3) promote a pleasant and home-like environment that is attractively furnished and decorated, and is of good acoustical quality; and

(4) be designed to stimulate maximum self-development, social interaction, comfort, and pleasure.

(g) Dining arrangements shall be based upon a rational plan to meet the needs of the residents and the requirements of their programs. Dining and serving arrangements should provide for a variety of eating experiences (for example, cafeteria and family style), and, when appropriate, for the opportunity to make food selections with guidance. Unless justified on the basis of meeting the program needs of the particular residents being served, dining tables should seat small groups of residents (typically four to six at a table), preferably including both sexes.

(h) Dining rooms shall be adequately supervised and staffed for the direction of self-help eating procedures, and to assure that each resident receives an adequate amount and variety of food. Staff members should be encouraged to eat with those residents who have semi-independent or independent eating skills. For residents not able to get to dining areas, food service practices shall permit and encourage maximum self-help, and shall promote social interaction and enjoyable experiences.

SEC. 244. (a) Residents shall be provided with systematic training to develop appropriate eating skills, utilizing adaptive equipment where it serves the developmental process.

(b) Residents with special eating disabilities shall be provided with an interdisciplinary approach to the diagnosis and remediation of their problems, consistent with their developmental needs.

(c) Direct-care staff shall be trained in and shall utilize proper feeding techniques. Residents shall eat in an upright position. Residents shall eat in a manner consistent with their developmental needs (for example, infants should be fed in arms, as appropriate). Residents shall be fed at a leisurely rate, and the time allowed for eating shall be such as to permit adequate nutrition, to promote the development of self-feeding abilities, to encourage socialization, and to provide a pleasant mealtime experience.

(d) Effective procedures for cleaning all equipment and all areas shall be followed consistently. Handwashing facilities, including hot and cold water, soap, and paper towels, shall be provided adjacent to work areas.

Subchapter III—Clothing

SEC. 245. (a) Each resident shall have an adequate allowance of neat, clean, fashionable, and seasonable clothing.

(b) Each resident shall have his or her own clothing, which is, when necessary, properly and inconspicuously marked with his or her name, and he or she shall use this clothing. Such clothing shall make it possible for residents to go out of doors in inclement weather, to go for trips or visits appropriately dressed, and to make a normal appearance in the community.

(c) Nonambulatory residents shall be dressed daily in their own clothing, including shoes, unless contraindicated in written medical orders.

(d) Washable clothing shall be designed for multihandicapped residents being trained in self-help skills, in accordance with individual needs.

(e) Clothing for incontinent residents shall be designed to foster comfortable sitting, crawling or walking, and toilet training.

(f) A current inventory should be kept of each resident's personal and clothing items.

(g) Residents shall be trained and encouraged to:

(1) select and purchase their own clothing as independently as possible, preferably utilizing community stores;

(2) select their daily clothing;

(3) dress themselves;

(4) change their clothes to suit the activities in which they engage; and

(5) maintain (launder, clean, mend) their clothing as independently as possible.

SEC. 246. Storage space for clothing to which the resident has access shall be provided. Ample closet and drawer space shall be provided for each resident. Such space shall be accessible to all, including those in wheelchairs.

SEC. 247. The person responsible for the residential facility's resident-clothing program shall be trained or experienced in the selection, purchase, and maintenance of clothing, including the design of clothing for the handicapped.

Subchapter IV—Health, Hygiene, and Grooming

SEC. 248. (a) Residents shall be trained to exercise maximum independence in health, hygiene, and grooming practices, including bathing, brushing teeth, shampooing, combing and brushing hair, shaving, and caring for toenails and fingernails.

(b) Each resident shall be assisted in learning normal grooming practices with individual toilet articles that are appropriately available to that resident.

(c) Teeth shall be brushed daily, with an effective dentifrice. Individual brushes shall be properly marked, used, and stored. Dental care practices should encourage the use of newer dental equipment, such as electric toothbrushes and water picks, as prescribed.

(d) Residents shall be regularly scheduled for hair cutting and styling, in an individualized, normalized manner, by trained personnel.

(e) For residents who require such assistance, cutting of toenails and fingernails by trained personnel shall be scheduled at regular intervals.

(f) Each resident shall have a shower or tub bath at least daily, unless medically contraindicated. Resident's bathing shall be conducted at the most independent level possible. Resident's bathing shall be conducted with due regard for privacy. Individual washcloths and towels shall be used. A bacteriostatic soap shall be used, unless otherwise prescribed.

(g) Female residents shall be helped to attain maximum independence in caring for menstrual needs. Menstrual supplies shall be of the same quality and diversity available to all women.

(h) Every resident who does not eliminate appropriately and independently shall be engaged in a toilet training program. The residential facility's training program shall be applied systematically and regularly. Appropriate dietary adaptations shall be made to promote normal evacuation and urination. The program shall comprise a hierarchy of procedures leading from incontinence to independent toileting. Records shall be kept of the progress of each resident receiving toilet training. Appropriate equipment shall be provided for toilet training, including equipment appropriate for the multiple handicapped. Residents who are incontinent shall be immediately bathed or cleansed, upon voiding or soiling, unless specifically contraindicated by the training program in which they are enrolled, and all soiled items shall be changed. Persons shall wash their hands after handling an incontinent resident.

(i) Each living unit shall have a properly adapted drinking unit. Residents shall be taught to use such units. Those residents who cannot be so taught shall be given the proper daily amount of fluid at appropriate intervals adequate to prevent dehydration. There shall be a drinking unit accessible to, and usable by, residents in wheelchairs. Special cups and noncollapsible straws shall be available when needed by the multiple handicapped. If the drinking unit employs cups, only single-use, disposable types shall be used.

(i) Procedures shall be established for:

(1) monthly weighing of residents, with greater frequency for those with special needs;

(2) quarterly measurement of height, until the age of maximum growth;

(3) maintenance of weight and height records; and

(4) every effort shall be made to assure that residents maintain normal weights.

(k) Policies and procedures for the care of residents with infections and contagious diseases shall conform to State and local health department regulations.

(l) Orders prescribing bed rest or prohibiting residents from being taken out of doors shall be reviewed by a physician at least every 3 days.

(m) Provisions shall be made to furnish and maintain in good repair, and to encourage the use of, dentures, eyeglasses, hearing aids, braces, and so forth, prescribed by appropriate specialists.

Subchapter V—Grouping and Organization of Living Units

SEC. 249. (a) Living unit components or groupings shall be small enough to insure the development of meaningful interpersonal relationships among residents and between residents and staff. The resident-living unit (self-contained unit including sleeping, dining, and activity areas) should provide for not more than 16 residents. Any deviation from this size should be justified on the basis of meeting the program needs of the specific residents being served. To maximize development, residents should be grouped within the living unit into program groups of not more than eight. Any deviation from this size should be justified on the basis of meeting the program needs of the specific residents being served.

(b) Residential units or complexes should house both male and female residents to the extent that this conforms to the prevailing cultural norms. Residents of grossly different ages, developmental levels, and social needs shall not be housed in close physical or social proximity, unless such housing is planned to promote the growth and development of all those housed together. Residents who are mobile-nonambulatory, deaf, blind, or multihandicapped shall be integrated with peers of comparable social and intellectual development, and shall not be segregated on the basis of their handicaps.

(c) The living unit shall not be a self-contained program unit, and living unit activities shall be coordinated with recreation, educational, and habilitative activities in which residents engage outside the living unit, unless contraindicated by the specific program needs of the particular residents being served. Each program group should be assigned a specific person, who has responsibility for providing an organized, developmental program of physical care, training, and recreation.

(d) Residents shall be allowed free use of all living areas within the living unit, with due regard for privacy and personal possessions. Each resident shall have access to a quiet, private area where he can withdraw from the group when not specifically engaged in structured activities.

(e) Outdoor active play or recreation areas shall be readily accessible to all living units.

Subchapter VI—Resident-Living Staff

SEC. 250. (a) There shall be sufficient, appropriately qualified, and adequately trained personnel to conduct the resident-living program, in accordance with the standards specified in this section. Resident-living personnel shall be administratively responsible to a person whose training and experience is appropriate to the program. The title applied to the individuals who directly interact with residents in the living units should be appropriate to the kind of residents with whom they work and the kind of interaction in which they engage. The personnel who staff the living units may be referred to by a variety of terms, such as attendants, child care workers, or cottage parents. The term "psychiatric aid" may be appropriate for a unit serving the emotionally disturbed, but not for a cottage of well-adjusted children. The title of "child care worker" may be appropriate for a nursery school group, but not for an adult unit. Nurses' aides are appropriate for units serving sick residents but not well ones.

(b) The attire of resident-living personnel should be appropriate to the program of the unit in which they work, and consistent with attire worn in the community.

(c) When resident-living units are organized as recommended in subchapter V, and designed as stipulated in subchapter VII, the staff-resident ratios for 24-hour, 7-day coverage of such units by resident-living personnel, or for equivalent coverage, should be as follows:

(1) for medical and surgical units, and for units including infants, children (to puberty), adolescents requiring considerable adult guidance and supervision, severely and profoundly retarded or developmentally disabled, moderately and severely physically handicapped, and residents who are aggressive, assaultive, or security risks, or who manifest severely hyperactive or psychotic like behavior—

(A) first shift, 1 to 4;

(B) second shift, 1 to 4;

(C) third shift, 1 to 8; and

(D) overall ratio (allowing for a 5-day work week plus holiday, vacation, and sick time), 1 to 1;

(2) for units serving moderately retarded or developmentally disabled adolescents and adults requiring habit training—

(A) first shift, 1 to 8;

(B) second shift, 1 to 4;

(C) third shift, 1 to 8; and

(D) overall ratio, 1 to 1.25;

(3) for units serving residents in vocational training programs and adults who work in sheltered employment situations—

(A) first shift, 1 to 16;

(B) second shift, 1 to 8;

(C) third shift, 1 to 16; and

(D) overall ratio, 1 to 2.5.

(d) Regardless of the organization or design of resident-living units, the overall staff-resident ratios should be as stipulated above. Regardless of the organization or design of resident-living units, the overall staff-resident ratios for the categories defined above shall not be less than 1 to 2, 1 to 2.5, and 1 to 5, respectively.

Subchapter VII—Design and Furnishing of Living Units

SEC. 251. (a) The design, construction, and furnishing of resident-living units shall be—

(1) appropriate for the fostering of personal and social development;

(2) appropriate to the program;

(3) flexible enough to accommodate variations in program to meet changing needs of residents; and

(4) such as to minimize noise and permit communication at normal conversation levels.

(b) The interior design of living units shall simulate the functional arrangements of a home to encourage a personalized atmosphere for small groups of residents, unless it has been demonstrated that another arrangement is more effective in maximizing the human qualities of the specific residents being served. There shall be a minimum of 80 square feet of living, dining, or activity space for each resident. This space shall be arranged to permit residents to participate in different kinds of activities, both in groups and singly. Furniture and furnishings shall be safe, appropriate, comfortable, and homelike.

(c) Bedrooms shall:

(1) be on or above street grade level;

(2) be outside rooms;

(3) accommodate from one to four residents;

(4) provide at least 60 square feet per resident in multiple sleeping rooms, and not less than 80 square feet in single rooms;

(5) partitions defining each bedroom shall extend from floor to ceiling;

(6) doors to bedrooms—

(A) should not have vision panels;

(B) should not be lockable, except where residents may lock their own bedroom doors, as consistent with their program;

(7) there shall be provision for residents to mount pictures on bedroom walls (for example, by means of pegboard or cork strips), and to have flowers, artwork, and other decorations;

(8) each resident shall be provided with—

(A) a separate bed of proper size and height for the convenience of the resident;

(B) a clean, comfortable mattress;

(C) bedding appropriate for weather and climate;

(9) each resident shall be provided with—

(A) appropriate individual furniture, such as a chest of drawers, a table or desk, and an individual closet with clothes racks and shelves accessible to the resident;

(B) a place of his or her own for personal play equipment and individually prescribed prosthetic equipment; and

(10) space shall be provided for equipment for daily out-of-bed activity for all residents not yet mobile, except those who have a short-term illness, or those very few for whom out-of-bed activity is a threat to life.

(d) Suitable storage shall be provided for personal possessions, such as toys, books, pictures, games, radios, arts and crafts materials, toiletries, jewelry, letters, and other articles and equipment, so that they are accessible to the residents for their use. Storage areas shall be available for off-season personal belongings, clothing, and luggage.

(e) Toilet areas, clothes closets, and other facilities shall be located and equipped so as to facilitate training toward maximum self-help by residents, including the severely and profoundly retarded or developmentally disabled and the multiple handicapped as follows:

(1) water closets, showers, bathtubs, and lavatories shall approximate normal patterns found in homes, unless specifically contraindicated by program needs;

(2) toilets, bathtubs, and showers shall provide for individual privacy (with partitions and doors), unless specifically contraindicated by program needs;

(3) water closets and bathing and toileting appliances shall be equipped for use by the physically handicapped;

(4) there shall be at least one water closet of appropriate size for each six residents;

(A) at least one water closet in each living unit shall be accessible to residents in wheelchairs;

(B) each water closet shall be equipped with a toilet seat;

(C) toilet tissue shall be readily accessible at each water closet;

(5) there shall be at least one lavatory for each six residents and one lavatory shall be accessible to and usable by residents in wheelchairs;

(6) there shall be at least one tub or shower for each eight residents;

(7) there shall be individual racks or other drying space for washcloths and towels; and

(8) larger, tilted mirrors shall be available to residents in wheelchairs.

(f) Provisions for the safety, sanitation, and comfort of the residents shall comply with the following requirements:

(1) each habitable room shall have direct outside ventilation by means of windows, louvres, air-conditioning, or mechanical ventilation horizontally and vertically;

(2) each habitable room shall have at least one window, and the window space in each habitable room should be at least one-eighth (12½ percent) of the floor space;

(A) each resident unit of eight shall have at least one glazed area low enough so that a child in normal day activities has horizontal visual access to the out of doors;

(B) the type of glass or other glazing material used shall be appropriate to the safety needs of the residents of the unit;

(3) floors shall provide a resilient, comfortable, attractive, nonabrasive, and slip-resistant surface. Carpeting used in units serving residents who crawl or creep shall be nonabrasive;

(4) temperature and humidity shall be maintained within a normal comfort range by heating, air-conditioning, or other means. The heating apparatus employed shall not constitute a burn hazard to the residents;

(5) the temperature of the hot water at all taps to which residents have access shall be controlled, by the use of thermostatically controlled mixing valves or by other means, so that it does not exceed 110 degrees Fahrenheit. Mixing valves shall be equipped with safety

alarms that provide both auditory and visual signals of valve failure;

(6) emergency lighting of stairs and exits, with automatic switches, shall be provided in units housing more than 15 residents;

(7) there shall be adequate clean linen and dirty linen storage areas for each living unit. Dirty linen and laundry shall be removed from the living unit daily; and

(8) laundry and trash chutes are discouraged, but, if installed, such chutes shall comply with regulations proscribed by the Secretary.

Chapter 3.—PROFESSIONAL AND SPECIAL PROGRAMS AND SERVICES

Subchapter I—Introduction

Sec. 252. (a) In addition to the resident-living services otherwise detailed in this title, residents shall be provided with the professional and special programs and services detailed in this section, in accordance with their needs for such programs and services.

(b) The professional and special programs and services detailed herein may be provided by programs maintained or personnel employed by the residential facility, or by formal arrangements between the residential facility and other agencies or persons, whereby the latter will provide such programs and services to the residential facility's residents as needed.

(c) In accordance with the normalized principle, all professional services to the mentally retarded and other individuals with developmental disabilities should be rendered in the community, whenever possible, rather than in a residential facility, and where rendered in a residential facility, such services must be at least comparable to those provided the nonretarded in the community.

(d) Programs and services provided by the residential facility or to the residential facility by agencies outside it, or by persons not employed by it, shall meet the standards for quality of service as stated in this section. The residential facility shall require that services provided its residents meet the standards for quality of services as stated in this section, and all contracts for the provision of such services shall stipulate that these standards will be met.

SEC. 253. (a) Individuals providing professional and special programs and services to residents may be identified with the following professions, disciplines, or areas of service:

(1) audiology;

(2) dentistry (including services rendered by licensed dentists, licensed dental hygienists, and dental assistants);

(3) education;

(4) food and nutrition (including services rendered by dietitians and nutritionists);

(5) library services;

(6) medicine (including services rendered by licensed physicians, whether doctors of medicine or doctors of osteopathy, licensed podiatrists, and licensed optometrists);

(7) music, art, dance, and other activity therapies;

(8) nursing;

(9) occupational therapy;

(10) pharmacy;

(11) physical therapy;

(12) psychology;

(13) recreation;

(14) religion (including services rendered by clergy and religious educators);

(15) social work;

(16) speech pathology;

(17) vocational rehabilitation counseling; and

(18) volunteer services.

(b) Interdisciplinary teams for evaluating the resident's needs, planning an individualized habilitation program to meet identified needs, and periodically reviewing the resident's response to his program and revising the program accordingly, shall be constituted of persons drawn from, or representing, such of the aforementioned professions, disciplines, or service areas as are relevant in each particular case.

(c) Since many identical or similar services or functions may competently be rendered by individuals of different professions, the standards in the following subsections shall be interpreted to mean that necessary services are to be provided in efficient and competent fashion, without regard to the professional identifications of the persons providing them, unless only members of a single profession are qualified or legally authorized to perform the stated service. Services listed under the duties of one profession may, therefore, be rendered by members of other professions who are equipped by training and experience to do so.

(d) Regardless of the means by which the residential facility makes professional services available to its residents, there shall be evidence that members of professional disciplines work together in cooperative, coordinated, interdisciplinary fashion to achieve the objective of the residential facility.

SEC. 254. Programs and services and the pattern of staff organization and function within the residential facility shall be focused upon serving the individual needs of residents and should provide for—

(1) comprehensive diagnosis and evaluation of each resident as a basis for planning programing and management;

(2) design and implementation of an individualized habilitation program to effectively meet the needs of each resident;

(3) regular review, evaluation, and revision, as necessary, of each individual's habilitation program;

(4) freedom of movement of individual residents from one level of achievement to another, within the facility and also out of the residential facility, through training, habilitation, and placement; and

(5) an array of those services that will enable each resident to develop to his maximum potential.

Subchapter II—Dental Services

SEC. 255. (a) Dental services shall be provided all residents in order to maximize their general health by—

(1) maintaining an optimal level of daily oral health, through preventive measures; and

(2) correcting existing oral diseases.

(b) Dental services shall be rendered—

(1) directly, through personal contact with all residents by dentists, dental hygienists, dental assistants, dental health educators, and oral hygiene aides, as appropriate to the size of the residential facility; and

(2) indirectly, through contact between dental staff and other personnel caring for the residents, in order to maintain their optimal oral health.

(c) Dental services available to the residential facility should include—

(1) dental evaluation and diagnosis;

(2) dental treatment;

(3) comprehensive preventive dentistry programs;

(4) education and training in the maintenance of oral health;

(5) participation, as appropriate, by dentists and dental hygienists in the continuing evaluation of individual residents by interdisciplinary teams, to initiate, monitor, and follow up individualized habilitation programs;

(6) consultation with, or relating to—

(A) residents;

(B) families of residents;

(C) other residential facility services and personnel;

(7) participation on appropriate residential facility committees; and

(8) planning and conducting dental research; cooperating in interdisciplinary research; and interpret-

ing, disseminating, and implementing applicable research findings.

(d) Comprehensive diagnostic services for all residents shall include—

(1) a complete extra- and intraoral examination, utilizing all diagnostic aids necessary to properly evaluate the resident's oral condition, within a period of 1 month following admission;

(2) provision for adequate consultation in dentistry and other fields, so as to properly evaluate the ability of the patient to accept the treatment plan that results from the diagnosis; and

(3) a recall system that will assure that each resident is reexamined at specified intervals in accordance with his needs, but at least annually.

(e) Comprehensive treatment services for all residents shall include—

(1) provision for dental treatment, including the dental specialties of pedodontics, orthodontics, periodontics, prosthodontics, endodontics, oral surgery, and oral medicine, as indicated; and

(2) provision for emergency treatment on a 24-hour, 7-days-a-week basis, by a qualified dentist.

(f) Comprehensive preventive dentistry programs should include—

(1) fluoridation of the residential facility's water supply;

(2) topical and systematic fluoride therapy, as prescribed by the dentist;

(3) periodic oral prophylaxis, by a dentist or dental hygienist, for each resident;

(4) provisions for daily oral care, as prescribed by a dentist or dental hygienist, including:

(A) toothbrushing and toothbrushing aids, such as disclosing wafers;

(B) tooth flossing;

(C) irrigation;

(D) proper maintenance of oral hygiene equipment;

(E) monitoring the program to assure its effectiveness; and

(5) provision, wherever possible, of diets in a form that stimulates chewing and improvement of oral health.

(g) Education and training in the maintenance of oral health shall include:

(1) continuing inservice training of living-unit personnel in providing proper daily oral health care for residents;

(2) providing dental health education to direct-care personnel;

(3) a dental hygiene program that includes:

(A) discovery, development, and utilization of specialized teaching techniques that are effective for individual residents;

(B) importing information regarding nutrition and diet control measures to residents and staff;

(C) instruction of classroom teachers or students in proper oral hygiene methods;

(D) motivation of teachers and students to promote and maintain good oral hygiene;

(E) instruction of residents in living units in proper oral hygiene methods; and

(4) instruction of parents or surrogates in the maintenance of proper oral hygiene, where appropriate (as in the case of residential facilities having day programs, or in the case of residents leaving the residential facility).

(h) A permanent dental record shall be maintained for each resident. A summary dental progress report shall be entered in the resident's unit record at stated intervals. A copy of the permanent dental record shall be provided a residential facility to which a resident is transferred.

(i) When the residential facility has its own dental staff, there should be a manual that states the philosophy of the dental service and describes all dental procedures and policies. There shall be a formal arrangement for providing qualified and adequate dental services to the residential facility, including care for dental emergencies on a 24-hour, 7-days-a-week basis. A dentist, fully licensed to practice in the State in which the residential facility is located, shall be designated to be responsible for maintaining standards of professional and ethical practice in the rendering of dental services to the residential facility. Where appropriate, the residential facility should, in addition, have available to it, and should utilize the program-development consultation services of a qualified dentist who has experience in the field of dentistry for the retarded and other individuals with developmental disabilities.

(j) There shall be available sufficient, appropriately qualified dental personnel, and necessary supporting staff, to carry out the dental services program. All dentists providing services to the residential facility shall be fully licensed to practice in the State in which the residential facility is located. All dental hygienists providing services to the residential facility shall be licensed to practice in the State in which the residential facility is located. Dental assistants should be certified by an appropriate nationally recognized professional association or should be enrolled in a program leading to certification. Dental health educators shall have a thorough knowledge of—

(1) dental health; and

(2) teaching methods.

(k) Oral hygiene aides, who may supplement and promote the proper daily oral care of residents, through actual participation and development of new methods in the toothbrushing program, or in the dissemination of oral hygiene information, should be—

(1) thoroughly trained in current concepts and procedures of oral care; and

(2) trained to recognize abnormal oral conditions.

(l) Supporting staff should include, as appropriate to the program—

(1) receptionists;

(2) clerical personnel to maintain current dental records;

(3) dental laboratory technicians certified by the appropriate nationally recognized professional association;

(4) escort aides; and

(5) janitorial or housekeeping personnel.

(m) All dentists providing service to the residential facility shall adhere to the code of ethics published by the appropriate nationally recognized professional association.

SEC. 256. (a) Appropriate to the size of the residential facility, a continuing education program shall be provided that is designed to maintain and improve the skills and knowledge of its professional dental personnel, through means including but not limited to:

(1) preceptor or other orientation programs;

(2) participation in seminars, workshops, conferences, institutes, or college or university courses, to the extent of at least 60 clock hours annually for each dental professional, in accordance with the standards of the nationally recognized professional dental association and its component societies;

(3) study leave;

(4) participation in the activities of professional organizations that have as their goals the furtherance of expertise in the treatment of the handicapped;

(5) access to adequate library resources, including current and relevant books and journals in dentistry, dental hygiene, dental assisting, mental retardation, and developmental disabilities;

(6) encouragement of dentists to qualify themselves for staff privileges in hospitals; and

(7) sharing of information concerning dentistry in its relationship with mental retardation and developmental disabilities as by publication.

(b) To enrich and stimulate the residential facility's dental program, and to facilitate its integration with community services, the residential facility with, and provide educational experiences for the dental-career students of, dental schools, universities, colleges, technical schools, and hospitals, whenever the best interests of the residential facility's residents are thereby served.

(c) There shall be adequate space, facilities, and equipment to meet the professional, educational, and administrative needs of the dental service. General anesthesia facilities for dental care shall be available. The services of a certified dental laboratory shall be available. Appropriate dental consultation shall be employed in the planning, design, and equipage of new dental facilities, and in the modification of existing facilities. All dental facilities shall be free of architectural barriers for physically handicapped residents.

Subchapter III—Educational Services

SEC. 257. (a) Educational services, defined as deliberate attempts to facilitate the intellectual, sensorimotor, and effective development of the individual, shall be available to all residents, regardless of chronological age, degree of retardation, or accompanying disabilities or handicaps. There shall be a written statement of educational objectives that are consistent with the residential facility's philosophy and goals. The principle that learning begins at birth shall be recognized, and the expertise of early childhood educators shall be integrated into the interdisciplinary evaluation and programing for residents.

(b) Educational services available to the residential facility shall include but not be limited to—

(1) establishment and implementation of individual educational programs providing:

(A) continuous evaluation and assessment of the individual;

(B) programing for the individual;

(C) instruction of individuals and groups;

(D) evaluation and improvement of instructional programs and procedures;

(2) participation in program development services, including those relating to:

(A) resident habilitation;

(B) staff training;

(C) community activities;

(3) consultation with, or relating to:

(A) other programs for residents and staff;

(B) parents of residents;

(C) administration and operation of the residential facility;

(D) the community served by the residential facility; and

(4) research relating to educational programs, procedures, and techniques; and the interpretation, dissemination, and application of applicable research findings.

(c) Where appropriate, an educator shall be a member of the interdisciplinary teams or groups concerned with—

(1) the total programing of each resident; and

(2) the planning and development of the residential facility's programs for residents.

(d) Individual educational evaluations of residents shall:

(1) commence with the admission of the resident;

(2) be conducted at least annually;

(3) be based upon the use of empirically reliable and valid instruments, whenever such tools are available;

(4) provide the basis for prescribing an appropriate program of learning experiences for the resident;

(5) provide the basis for revising the individual prescription as needed;

(6) the reporting and dissemination of evaluation results shall be done in such a manner as to—

(A) render the content of the report meaningful and useful to its intended recipient and user; and

(B) promptly provide information useful to staff working directly with the resident.

(e) There shall be written educational objectives for each resident that are—

(1) based upon complete and relevant diagnostic and prognostic data;

(2) stated in specific behavioral terms that permit the progress of the individual to be assessed; and

(3) adequate for the implementation, continuing assessment, and revision, as necessary, of an individually prescribed program.

(f) There shall be evidence of educational activities designed to meet the educational objectives set for every resident. There shall be a functional educational record for each resident, maintained by, and available to, the educator.

(g) There shall be appropriate programs to implement the residential facility's educational objectives. Wherever local resources permit and the needs of the resident are served, residents should attend educational programs in the community. Educable and trainable residents shall be provided an educational program of a quality not less than that provided by public school programs for comparable pupils, as regards:

(1) physical facilities;

(2) qualifications of personnel;

(3) length of the school day;

(4) length of school year;

(5) class size;

(6) provision of instructional materials and supplies; and

(7) availability of evaluative and other ancillary services.

(h) Educational programs shall be provided to severely and profoundly retarded or developmentally disabled residents, and all other residents for whom educational provisions may not be required by State laws, irrespective of age or ability.

(i) Appropriate educational programs shall be provided residents with hearing, vision, perceptual, or motor impairments, in cooperation with appropriate staff.

(j) Educational programs should include opportunities for physical education, health education, music education, and art education, in accordance with the needs of the residents being served.

(k) A full range of instructional materials and media shall be readily accessible to the educational staff of the residential facility.

(l) Educational programs shall provide coeducational experiences. Learning activities in the classroom shall be coordinated with activities of daily living in the living units and with other programs of the residential facility and the community. The residential facility shall seek reciprocal services to and from the community, within the bounds of legality and propriety. An educational program operated by a residential facility shall seek consultation from educational agencies not directly associated with the residential facility.

SEC. 258. (a) There shall be available sufficient, appropriately qualified educational personnel, and necessary supporting staff, to carry out the educational programs. Delivery of educational services shall be the responsibility of a person who is eligible for—

(1) certification as a special educator of the mentally retarded or other individuals with developmental disabilities; and

(2) the credential required for a comparable supervisory or administrative position in the community.

(b) Teachers shall be provided aides or assistants, as needed. The residential facility's educators shall adhere to a code of ethics prescribed by the Secretary. Appropriate to the nature and size of the residential facility, there shall be an ongoing program for staff development specifically designed for educators. Staff members shall be encouraged to participate actively in professional organizations related to their responsibilities,

(c) To enrich and stimulate the residential facility's educational program, and to facilitate its integration with community services, opportunities for internships, student teaching, and practical experiences should be made available, in cooperation with university teacher-training programs, whenever the best interests of the residents are thereby served.

Subchapter IV—Food and Nutrition Services

SEC. 259. (a) Food and nutrition services shall be provided in order to—

(1) insure optimal nutritional status of each resident, thereby enhancing his or her physical, emotional, and social well-being; and

(2) provide a nutritionally adequate diet, in a form consistent with developmental level, to meet the dietary needs of each resident.

(b) There shall be a written statement of policies and procedures that—

(1) describes the implementation of the stated objectives of the food and nutrition services;

(2) governs the functions and programs of the food and nutrition services;

(3) is formulated and periodically reviewed by professional nutrition personnel;

(4) is prepared in consultation with other professional staff;

(5) is consistent with the residential facility's goals and policies;

(6) is distributed and interpreted to all residential facility personnel; and

(7) complies with State and local regulations.

(c) Whenever appropriate, the following services should be provided—

(1) initial and periodic evaluation of the nutritional status of each resident, including—

(A) determination of dietary requirements and assessments of intake and adequacy through—

(i) dietary interview;

(ii) clinical evaluation;

(iii) biochemical assessment;

(B) assessment of food service practices;

(C) assessment of feeding practices, capabilities, and potential;

(2) maintenance of a continuing and periodically reviewed nutrition record for each resident;

(3) incorporation of recommendations drawn from the nutrition evaluation into the total management plans for the resident;

(4) periodic review of implementation of recommendations and of need of modification;

(5) participation in the continuing interdisciplinary evaluation of individual residents, for the purposes of initiation, monitoring, and followup of individualized habilitation programs;

(6) provision of—

(A) counseling services to the individual resident;

(B) reciprocal consultation with residential facility staff and students;

(C) counseling service to residents' families or their surrogates;

(D) nutrition education, on a continuing basis, for residents, families or surrogates, staff, and students, and development of such programs in coordination with various education programs within the residential facility and the community;

(7) coordination of nutrition programs between the residential facility and the community, including—

(A) development of awareness of available programs in nutrition;

(B) development of needed nutrition programs;

(C) encouragement of participation of professionals and students in nutrition programs for the mentally retarded and developmentally disabled; and

(8) development, coordination, and direction of nutrition research, as well as cooperation in interdisciplinary research.

(d) Food services shall include—

(1) menu planning;

(2) initiating food orders or requisitions;

(3) establishing specifications for food purchases, and insuring that such specifications are met;

(4) storing and handling of food;

(5) food preparation;

(6) food serving;

(7) maintaining sanitary standards in compliance with State and local regulations; and

(8) orientation, training, and supervision of food service personnel.

(e) The food and nutrition needs of residents shall be met in accordance with the recommended dietary allowances of the food and nutrition board of the national research council, adjusted for age, sex, activity, and disability, through a nourishing, well-balanced diet. The total food intake of the resident should be evaluated, including food consumed outside of as well as within the residential facility.

(f) Menus shall be planned to meet the needs of the residents in accordance with subsection (e). Menus shall be written in advance. The daily menu shall be posted in food preparation areas. When changes in the menu are necessary, substitutions should be noted and should provide equal nutritive values. Menus shall provide sufficient variety of foods served in adequate amounts at each meal, and shall be: (1) Different for the same days of each week; (2) Adjusted for seasonal changes. Records of menus as served shall be filed and maintained for at least 30 days. At least a 1-week supply of staple foods and a 2-day supply of perishable foods shall be maintained on the premises. Records of food purchased for preparation shall be filed and maintained for at least 30 days. A file of tested recipes adjusted to appropriate yield should be maintained.

(g) Foods shall be prepared by methods that—

(1) conserve nutritive value;

(2) enhance flavor; and

(3) enhance appearance.

(h) Food shall be prepared, stored, and distributed in a manner that assures a high quality of sanitation. Effective procedures for cleaning all equipment and work areas shall be followed consistently. Dishwashing and panwashing shall be carried out in compliance with State and local health codes. Handwashing facilities, including hot and cold water, soap, and paper towels, shall be provided adjacent to work area.

(i) When food is transported, it shall be done in a manner that maintains proper temperature, protects the food from contamination and spoilage, and insures the preservation of nutritive value. Food storage procedures shall meet State and local regulations. Dry or staple food items shall be stored at least 12 inches above the floor, in a ventilated room not subject to sewage or waste water backflow, or contamination by condensation, leakage, rodents, or vermin. Perishable foods shall be stored at the proper temperatures to preserve nutritive values. Food served to residents and not consumed shall be discarded.

(j) There shall be a sufficient number of competent personnel to fulfill the objectives of the food and nutrition services, including—

(1) nutritionists or dietitians;

(2) other food service personnel;

(3) clerical personnel;

(4) depending upon the size and scope of the residential facility, food and nutrition services shall be directed by one of the following—

(A) a dietitian who is eligible for membership in the appropriate professional dietetic association and preferably eligible for registration by such association, or a nutritionist who has a master's degree in foods, nutrition, or public health nutrition, who is eligible for membership in the appropriate professional dietetic association, and preferably eligible for registration by the association, and who, unless employed by a residential facility that also employs a dietitian, has had experience in institutional food management;

(B) a food service manager who has a bachelor's degree in foods, nutrition, or a related field, and who receives consultation from a dietary consultant;

(C) a responsible person who has had training and experience in meal management and service, and who receives consultation from a dietary consultant; and

(D) the person responsible for food and nutrition services should have had training or experience in providing services to the mentally retarded, and other individuals with developmental disabilities and should be sensitive to their needs;

(5) the dietary consultant shall—

(A) be eligible for membership in the appropriate professional dietetic association, and preferably eligible for registration by such association;

(B) serve on a regularly scheduled and frequent basis when no full-time dietitian is available; and

(6) every person engaged in the preparation and serving of food in the residential facility shall have a valid food handler's permit, as required by State or local regulations. No person who is afflicted with a disease in a communicable stage, or who is a carrier of a communicable disease, or who has an open wound, shall work in any food service operation. Every person engaged in the preparation and serving of food in the residential facility shall annually be medically determined to be free of any disease in a communicable stage. All dietitians and nutritionists shall adhere to the code of ethics of the appropriate professional dietetic association.

(k) Appropriate to the size of the residential facility, an ongoing inservice training program shall be conducted that is designed to improve and maintain the skills of its food and nutrition services staff, through means such as—

(1) seminars, workshops, conferences, and institutes;

(2) college and university courses;

(3) participation in professional organizations;

(4) participation in interdisciplinary groups;

(5) visitations to other residential facilities; and

(6) access to adequate library resources, including current and relevant books and journals in nutrition and mental retardation.

(l) Opportunities should be provided, in cooperation with university and other training programs, for students to obtain practical experience, under appropriate supervision, whenever the best interests of the residents are thereby served.

(m) There shall be adequate space, facilities, and equipment to fulfill the professional, educational, administrative, operational, and research needs of the food and nutrition services. Dining areas and facilities for food storage, preparation, and distribution shall be—

(1) designed in cooperation with a dietitian and, when appropriate, with assistance from a qualified food service and equipment consultant;

(2) adequate for the storage and preservation of food;

(3) in compliance with State and local sanitation and other requirements;

(4) adequate for the preparation and serving of food; and

(5) adequate for sanitary storage for all dishes and equipment.

Subchapter V—Library Services

Sec. 260. (a) Library services, which include the location, acquisition, organization, utilization, retrieval, and delivery of materials in a variety of media, shall be available to the residential facility, in order to support and strengthen its total habilitation program by providing complete and integrated multimedia information services to both staff and residents. Library services shall make available to the residential facility the resources of local, regional, State, and National library systems and networks. Library services shall be available to all residents, regardless of chronological age, degree of retardation, level of communication skills, or accompanying disabilities or handicaps.

(b) Library services to residents shall be rendered—

(1) directly, through personal contact between library staff and residents;

(2) indirectly, through contact between librarians and other persons working with the residents, designed to—

(A) maintain an atmosphere that recognizes the rights of the resident to access to information and to personal use of library materials appropriate to his level of development in communication skills or to his desire to conform to peer groups; and

(B) enhance interpersonal relationships between direct-care workers and residents, through the mutual enjoyment of written, recorded, or oral literature appropriate to the resident's level of development and preference.

(c) Library services available to residents should include—

(1) assistance in team evaluation and assessment of the individual's level of development in communication skills, such as listening, comprehension, reading, and ability to respond to stimuli in a wide range and variety of media;

(2) provision of informational, recreational, and educational materials appropriate to individual residents at all stages of development in communication skills, including media to stimulate sensory development, both in the library and in the living unit. Such materials should include, but need not be limited to—

(A) books, including picture, juvenile, adult, high interest-low vocabulary, large print, and talking books;

(B) magazines, including juvenile, adult pictorial, and magazines on talking books;

(C) newspapers;

(D) audiovisual media, including films, filmstrips, slides, video tapes, audio tapes, and records, and appropriate equipment;

(E) graphics;

(F) experience materials, such as manipulative materials, toys and games, realia, and animals;

(3) development of programs for individual or group enjoyment, for development of communication skills, for encouragement and satisfaction of natural human curiosity about anything, including sex and the facts of life, and for general enhancement of self-image. These programs should include, but need not be limited to—

(A) storytelling with listener participation through games or other activities;

(B) reading aloud, including "reading" pictures;

(C) film or filmstrip programs;

(D) listening to recorded media;

(E) media discussion groups;

(F) library clubs;

(G) touching, browsing, exploring, or naming sensory stimuli;

(H) creative writing, including group composition through dictation, tape recording, etc.;

(I) puppetry, including the making of puppets;

(J) creative dramatics;

(4) opportunities to visit, and make use of, community library services and facilities in the same manner, and on the same terms, as any resident of the community;

(5) referral services to the community library most convenient to place of residence or employment, when the resident leaves the residential facility; and

(6) active participation in, and encouragement of, library programs related to the educational and habilitative services of the residential facility, including the supplementation, support, and reinforcement of school programs.

(d) Librarians providing services to residents should act as advocates on their behalf if residential facility policies or community library policies interfere with the retarded or developmentally disabled person's freedom to read materials of his own choosing or if they deny or abrogate his right to information or access to library services of any kind, in accordance with the standards adopted by the appropriate professional library association.

(e) Library services to staff should include—

(1) selection, acquisition, organization, classification, cataloging, procurement through interlibrary loan, and dissemination of informational, educational, and instructional library materials and audiovisual equipment;

(2) provision of reference and bibliographic materials and services, literature searches, bibliography compilation, indexing and abstracting services, and other

guides to the literature relevant to mental retardation and developmental disabilities;

(3) acquisition of materials for evaluation for purchase;

(4) provision of a current awareness program to alert staff to new materials and developments in their fields;

(5) orientation to library services and functions, including continuing instruction and assistance in the use of informational sources, and participation in general orientations to the residential facility;

(6) provision of written and oral translation services; and

(7) cooperation in inservice training programs by working with subject specialists and by recommending, providing, or producing materials in various media.

(f) Library services to the residential facility may include—

(1) provision of informational materials about the residential facility and mental retardation developmental disabilities in general, through an organized collection of resources;

(2) assistance with such public relation functions as preparing brochures, program statements, annual reports, writing news releases and feature stories, and

offering editorial and research assistance to staff preparing professional books and papers; and

(3) assistance in preparing grant applications and report writing.

(g) When library services are provided in the residential facility—

(1) there shall be a written statement of objectives that make possible a well-conceived, comprehensive, long-range program of library development, consistent with the overall goals of the residential facility, adapted to the needs and aptitudes of the residents, and designed to be modified as the program of the residential facility changes;

(2) there shall be a separate budget, adequate to carry out the program in accordance with stated goals and objectives;

(3) library services shall be placed within the organizational structure of the residential facility in such a way as to be available to, and maximally utilized by, all relevant services and programs;

(4) there shall be written policies covering the library's day-to-day activities, and the coordination of these activities with those of other services of the residential facility and with related activities in the community;

(5) there shall be available sufficient, appropriately qualified staff, and necessary supporting personnel, to carry out the program in accordance with stated goals and objectives;

(6) a qualified librarian shall be responsible for all library services. Where the level of need for services does not require the full-time employment of a professional librarian, coverage may be through the use of consultant service or supervisory personnel, through the pooling of resources and the sharing of services by two or more residential facilities in a geographic area, or through service supplied through a regional library system;

(7) the librarian shall participate, when appropriate, in the interdisciplinary planning, development, and evaluation of residential facility programs;

(8) the librarian should coordinate the purchasing of all print and nonprint materials for the residential facility, and act as the residential facility's informed agent in initiating the purchase of print and nonprint materials, and the library should serve as a clearinghouse for such holdings;

(9) librarians should participate in—

(A) educating appropriate members of the community, concerning the library needs of residents;

(B) planning, with community librarians, the utilization of library resources to optimize resident adjustment;

(C) developing appropriate expectancies and attitudes within community libraries that residents will use;

(10) appropriate relationships with other libraries and community agencies shall be established to more effectively accomplish the library's service functions;

(11) appropriate to the size of the residential facility, there should be a staff development program designed to maintain and improve the skills of library services staff through means such as—

(A) staff meetings and inservice training;

(B) seminars, workshops, conferences, and institutes;

(C) college and university courses;

(D) professional organizations;

(E) participation in interdisciplinary groups;

(F) visits to other residential facilities;

(G) access to relevant professional literature;

(12) whenever appropriate, the library should provide training for beginning librarians, further the orientation and training of library assistants, technicians,

or volunteers, and serve as a training center for library institutes or workshops;

(13) library services should be located so as to be convenient and accessible to all users;

(14) all library functions should be integrated within a centralized location, whenever this does not act as a barrier to accessibility for any group;

(15) space, physical facilities, and equipment shall be adequate to carry out the program, and shall comply with the standards for library services in health care institutions published by the appropriate professional library association of hospitals and institutions of the appropriate professional library association;

(16) the hours during which the library is open should meet the requirements of the majority of the library's users, and should be as generous as possible; and

(17) users of library services shall participate in the planning and evaluation of library programs, by means such as advisory committees.

(h) If library services are provided outside the residential facility, there shall be a formal agreement that stipulates lines of communication, areas of responsibility, and kinds of service.

(i) The individual responsible for maintaining standards of professional and ethical practice in the rendering of library services to the residential facility—

(1) shall have a master's degree in library science from a school accredited by the recognized national professional library association; and

(2) should have preparation in a field relevant to work with the mentally retarded and other individuals with developmental disabilities.

(j) Individuals rendering library services, including librarians, media specialists, library and media technicians, supportive staff, and volunteers, shall have qualifications appropriate to their responsibilities and duties.

Subchapter VI—Medical Services

SEC. 261. (a) Medical services shall be provided in order to—

(1) achieve and maintain an optimal level of general health for each resident;

(2) maximize normal function and prevent disability; and

(3) facilitate the optimal development of each resident.

(b) Medical services shall be rendered—

(1) directly, through personal contact between physicians and residents; and

(2) indirectly, through contact between physicians and other persons working with the residents, which is designed to maintain an environment that recognizes and meets the health, hygiene, sanitary, and nutritional needs of the residents.

(c) Medical services available to the residential facility should include—

(1) evaluation and diagnosis;

(2) treatment;

(3) program development services, including those relating to—

(A) resident habilitation;

(B) staff training;

(C) community participation;

(4) consultation with, or relating to—

(A) residents;

(B) families of residents;

(C) the administration and operation of the residential facility;

(5) medical and ancillary staff training; and

(6) preventive health services for residents and staff.

(d) The services of medical and surgical hospitals that are accredited by the recognized national appropriate joint commission on accreditation of hospitals shall be available to residents. Only pathology, clinical laboratory, and radiologic services that meet the hospital accreditation standards of such joint commission on accreditation of hospitals shall be utilized. Electroencephalographic services shall be available as necessary. There shall be evidence, such as may be provided by a record of the deliberations of a utilization review committee, that such hospital and laboratory services are utilized in accordance with proper professional standards.

(e) Physicians shall participate, when appropriate—

(1) in the continuing interdisciplinary evaluation of individual residents, for the purposes of initiation, monitoring, and followup of individualized habilitation programs; and

(2) in the development for each resident of a detailed, written statement of—

(A) case management goals, encompassing the areas of physical and mental health, education, and functional and social competence; and

(B) a management plan detailing the various habilitation or rehabilitation modalities that are to be applied in order to achieve the specified goals, with clear designation of responsibility for implementation.

(f) The management plan shall ordinarily include, but not necessarily be limited to—

(1) the resident's day-to-day activity program;

(2) physical rehabilitation to prevent and correct deformity, to enhance mobility, and to facilitate training in self-help skills;

(3) provision for adaptive equipment necessary to the rehabilitation plan;

(4) an educational program;

(5) a vocation and occupational program;

(6) stated intervals for review of the management plan; and

(7) short- and long-term goals, including criteria for release.

(g) Statement of treatment goals and management plans shall be reviewed and updated—

(1) as needed, but at least annually; and

(2) to insure continuing appropriateness of the goals, consistency of management methods with the goals and the achievement of progress toward the goals.

(h) Special attention shall be given those residents who, without active intervention, are at risk of further loss of function, by means that include—

(1) early diagnosis of disease;

(2) prompt treatment in the early stages of disease;

(3) limitation of disability by arresting the disease process;

(4) prevention of complications and sequelae; and

(5) rehabilitation services to raise the affected individual to his or her greatest possible level of function, in spite of his or her handicap, by maximizing the use of his or her remaining capabilities.

(i) Preventive health services to residents shall include—

(1) means for the prompt detection and referral of health problems, through adequate medical surveillance, periodic inspection, and regular medical examination;

(2) annual physical examinations, that include—

(A) examination of vision and hearing;

(B) routine screening laboratory examinations, as determined by the physician, and special studies when the index of suspicion is high;

(3) maintenance of a graphic record of height and weight for each resident, in a form that permits ready reference to standardized norms;

(4) immunizations, using as a guide the recommendations of the United States Public Health Service Advisory Committee on Immunization Practices and of the appropriate committee on the control of infectious diseases of the appropriate medical specialty association;

(5) tuberculosis control, in accordance with the recommendations of the appropriate medical specialty association as appropriate to the residential facility's population; and

(6) reporting of communicable diseases and infections in accordance with law.

(j) Preventive health services to staff shall include—

(1) preemployment physical examinations; and

(2) surveys for the detection and prevention of communicable diseases.

(k) There shall be a formal arrangement for qualified medical care for the residential facility, including care for medical emergencies on a 24-hour, 7-days-a-week basis. A physician, fully licensed to practice medicine in the State in which the residential facility is located, shall be designated to be responsible for—

(1) maintaining standards of professional and ethical practice in the rendering of medical services in the residential facility; and

(2) maintaining the general health conditions and practices of the residential facility and/or system of health services.

Each resident shall have a personal (primary) physician, who maintains familiarity with his state of health and with conditions within the residential living unit that bear on his health. Qualified medical specialists of recognized professional ability shall be—

(1) available for a broad range of specialized care and consultation; and

(2) appropriately used.

(l) Appropriate to the size of the residential facility, an ongoing inservice training program shall be conducted that is designed to maintain and improve the medical skills of its physicians and their knowledge of development disabilities, through methods such as staff seminars, outside speakers, attendance at professional medical meetings, and informational exchanges with universities and teaching hospitals.

(m) There shall be adequate space, facilities, and equipment to fulfill the professional, educational, and administrative needs of the medical service.

Subchapter VII—Nursing Services

SEC. 262. (a) Residents shall be provided with nursing services, in accordance with their needs, in order to—

(1) develop and maintain an environment that will meet their total health needs;

(2) foster optimal health;

(3) encourage maximum self-care and independence; and

(4) provide skilled nursing care as needed.

(b) There shall be a written statement of nursing philosophy and objectives that are consistent with the purpose of the residential facility and that give direction to the nursing program. Nursing personnel shall be responsible for the formulation, review, and revision of the philosophy and objectives. The philosophy and objectives shall be—

(1) distributed to all nursing personnel; and

(2) made available and interpreted to all other personnel.

(c) Nursing services should be provided through—

(1) direct nursing intervention;

(2) instruction and supervision of residential facility staff rendering nursing care;

(3) supporting, counseling, and teaching the resident, his or her family, and his or her direct-care staff, at the residential facility or in the home;

(4) consultation and followthrough in the interest of the resident; and

(5) participation on appropriate residential facility committees.

(d) Nursing services to residents shall include, when appropriate—

(1) professional nurse participation in—

(A) the preadmission evaluation study and plan;

(B) the evaluation study, program design, and placement of the resident at the time of admission to the residential facility;

(C) the periodic reevaluation of the type, extent, and quality of services and programing;

(D) the development of discharge plans;

(E) the referral to appropriate community resources;

(2) services directed toward the promotion of health, including—

(A) observation and assessment of the developmental function of the resident, within his or her environment;

(B) training in habits of personal hygiene;

(C) family life and sex education;

(D) safety education;

(E) control of communicable diseases and infections, through—

(i) identification and assessment;

(ii) reporting to medical authority;

(iii) implementation of appropriate protective and preventive measures;

(F) development of a written plan for nursing action, in relation to the total habilitation program;

(G) modification of the nursing plan, in terms of the resident's daily needs, at least annually for adults and more frequently for children, in accordance with developmental changes;

(3) participation in the prevention of disability for all residents, with special attention to those residents who exhibit the lowest level of functional development including—

(A) nursing assessment of the functional level of development;

(B) development, implementation, and coordination of a plan to maintain and encourage optimal level of function, with written provision for direct and indirect nursing intervention; and

(4) planned, intensive nursing care for every resident who is medically determined to be acutely ill.

(e) A professional nurse shall participate, as appropriate, in the planning and implementation of training of residential facility personnel. Direct-care personnel shall be trained in—

(1) detecting signs of illness or dysfunction that warrant medical or nursing intervention;

(2) basic skills required to meet the health needs and problems of the residents; and

(3) first aid in the presence of accident or illness.

(f) Qualified nurses shall be encouraged to become involved in—

(1) initiating, conducting, and evaluating nursing research;

(2) evaluating and applying relevant research findings for the benefit of residents;

(3) formulating the policies governing research in the residential facility; and

(4) serving as resource persons to schools of nursing, and to public health nursing and related agencies.

(g) There shall be available sufficient, appropriately qualified nursing staff, which may include currently licensed practical nurses and other supporting personnel, to carry out the various nursing service activities. A registered professional nurse shall be designated as being responsible for maintaining standards of professional, legal, and ethical practice in the delivery of nursing services according to the needs of the residents. The individual responsible for the delivery of nursing services—

(1) should have at least a master's degree in nursing; and

(2) shall have knowledge and experience in the field of developmental disabilities.

(h) Nursing service personnel at all levels of experience and competence shall be—

(1) assigned responsibilities in accordance with their qualifications;

(2) delegated authority commensurate with their responsibility; and

(3) provided appropriate professional nursing supervision.

(i) Organized nursing services and professional nurse practitioners should have recourse to qualified and appropriate consultation as needed. All professional nurses shall be familiar with, and adhere to, the code of ethics published by the appropriate nationally recognized professional nurses' association.

(j) Appropriate to the size of the residential facility, there shall be an educational program designed to enhance the clinical competencies and the knowledge of developmental disabilities of its professional nursing staff, through means, including but not limited to—

(1) staff meetings and inservice training;

(2) seminars, workshops, conferences, and institutes;

(3) college and university courses;

(4) participation in professional organizations;

(5) participation in interdisciplinary groups;

(6) visits to other residential facilities; and

(7) access to relevant professional literature.

(k) To enrich and stimulate the residential facility's nursing program, and to facilitate its integration with community services, educational experiences for students of all types of professional and vocational nursing schools shall be encouraged and defined by a contractual agreement, whenever the best interests of the residents are thereby served.

(l) There shall be adequate space, facilities, and equipment to fulfill the professional, educational, and administrative needs of the nursing service. Professional nursing consultation shall be included in the design and modification of areas and residential facilities that will be used by the ill and the physically handicapped.

Subchapter VIII—Pharmacy Services

SEC. 263. (a) In order to contribute to improved resident care and to promote optimal response to drug therapy by the residents, through the full utilization of the knowledge and skills of the pharmacist, pharmacy services shall be provided under the direction of a qualified pharmacist. There shall be a formal arrangement for qualified pharmacy services, including provision for emergency service, by means appropriate to the residential facility. Such means may include the services of a pharmacist in a local community or hospital pharmacy that meets the standards listed herein, as well as the operation of its own pharmacy by the residential facility. There shall be a current pharmacy manual that—

(1) includes policies and procedures, and defines the functions and responsibilities relating to pharmacy services; and

(2) is revised annually to keep abreast of current developments in services and management techniques.

(b) There shall be a formulary system, approved by the responsible physician and pharmacist, and by other appropriate residential facility staff. Copies of the residential facility's formulary and of the nationally recognized American hospital formulary service shall be located and available, as appropriate to the residential facility.

(c) Upon admission of the resident, a medication history of prescription and nonprescription drugs used shall be obtained, preferably by the pharmacist, and his information shall be entered in the resident's record for the information of the staff. The pharmacist shall—

(1) receive the original, or a direct copy, of the physician's drug treatment order;

(2) review the drug regimen, and any changes, for potential adverse reactions, allergies, interactions, contraindications, rationality, and laboratory test modifications, and advise the physician of any recommended changes, with reasons and with an alternate drug regimen;

(3) maintain for each resident an individual record of all medications (prescription and nonprescription) dispensed, including quantities and frequency of refills;

(4) participate, as appropriate, in the continuing interdisciplinary evaluation of individual residents, for the purposes of initiation, monitoring, and followup of individualized habilitation programs;

(5) participate in any of the following activities that are undertaken in the residential facility:

(A) drug research;

(B) drug utilization review;

(C) infection and communicable disease committee;

(D) safety committee;

(E) patient care incident review; and

(6) establish quality specifications for drug purchases, and insure that they are met.

(d) The pharmacist should—

(1) prepare a drug treatment plan, as prescribed by the attending physician, for inclusion in the resident's record and for use by the staff, that includes—

(A) the drug product, dosage form, route of administration, and time of administration, including, when appropriate, the time with respect to meals, other drugs, and activities;

(B) a schedule of laboratory tests necessary to detect adverse reactions;

(C) noting of any potential adverse reactions for the staff's information;

(2) regularly review the record of each resident on medication, and have contact with selected residents with potential problems, noting in the residents' records and reporting to physicians any observations of response to drug therapy, and of adverse reactions and over or underutilization of drugs;

(3) provide instructions and counseling on the correct use of his or her drugs, as prescribed by the attending physician, to each resident on home visit and discharge, or to his or her parents;

(4) provide education and counseling to residents in independent living units on the correct use of their drugs, as prescribed by the attending physician, and

on the results expected from correct use and from over or underuse;

(5) participate in programs for sex education and drug abuse education;

(6) provide information on the resident's drug regimen to the receiving residential facility pharmacist, when the resident is transferred, and, with the approval of the resident or his or her guardian, to the resident's community pharmacist, his or her private physician, or the community mental retardation or developmental disability service when the resident is discharged from the residential facility, so as to insure continuity of care;

(7) participate in inservice education programs for professional and direct-care staff;

(8) orient and teach students in pharmacy and other professions, regarding pharmacy's services to the residents and regarding drugs and their uses; and

(9) participate in public educational and informational programs on mental retardation and developmental disabilities.

(e) Where appropriate to the residential facility, there shall be a pharmacy and therapeutics committee, that includes one or more pharmacists, to develop policy on drug usage in the residential facility, and to develop and maintain a current formulary. This committee shall meet not less than once every 3 months. Minutes of the committee meetings shall be kept on file.

(f) Written policies and procedures that govern the safe administration and handling of all drugs shall be developed by the responsible pharmacist, physician, nurse, and other professional staff, as appropriate to the residential facility. The compounding, packaging, labeling, and dispensing of drugs, including samples and investigational drugs, shall be done by the pharmacist, or under his direct supervision, with proper controls and records. Each drug shall be identified up to the point of administration. Procedures shall be established for obtaining drugs when the pharmacy is closed.

(g) The unit dose or individual prescription system of drug distribution should be used. Wherever possible, drugs that require dosage measurement shall be dispensed by the pharmacist in a form ready to be administered to the patient.

(h) There shall be a written policy regarding the administration of all drugs used by the residents, including those not specifically prescribed by the attending practitioner. There shall be a written policy regarding the routine of drug administration, including standardization of abbreviations indicating dose schedules. Medications shall not be used by any resident other than the one for whom they were issued. Only appropriately trained staff shall be allowed to administer drugs.

(i) There shall be a written policy governing the self-administration of drugs, whether prescribed or not.

(j) Drugs shall be stored under proper conditions of sanitation, temperature, light, moisture, ventilation, segregation, and security. All drugs shall be kept under lock and key except when authorized personnel are in attendance. The security requirements of Federal and State laws shall be satisfied in storerooms, pharmacies, and living units. Poisons, drugs used externally, and drugs taken internally shall be stored on separate shelves or in separate cabinets, at all locations. Medications that are stored in a refrigerator containing things other than drugs shall be kept in a separate compartment with proper security. A perpetual inventory shall be maintained of each narcotic drug in the pharmacy, and in each unit in which such drugs are kept, and inventory records shall show the quantities of receipts and issues and the person to whom issued or administered. If there is a drug storeroom separate from the pharmacy, there shall be a perpetual inventory of receipts and issues of all drugs by such storeroom.

(k) The pharmacist should review the drugs in each living unit monthly, and should remove outdated and deteriorated drugs and drugs not being used. Discontinued and outdated drugs, and containers with worn, illegible, or missing labels, shall be returned to the pharmacy for proper disposition.

(l) There shall be automatic stop orders on all drugs. There shall be a drug recall procedure that can be readily implemented. Medication errors and drug reactions shall be recorded and reported immediately to the practitioner who ordered the drug. There shall be a procedure for reporting adverse drug reactions to the Federal Food and Drug Administration. The pharmacist shall be responsible for the storage and dispensing of investigational drugs. The pharmacist shall provide the residential staff with pharmacological and other necessary information on investigational drugs, including dosage form, dosage range, storage, adverse reactions, usage, and contraindications.

(m) There shall be an emergency kit—

(1) readily available to each living unit; and

(2) constituted so as to be appropriate to the needs of its residents.

(n) Pharmacy services shall be—

(1) directed by a professionally competent and legally qualified pharmacist who is a graduate of a school of pharmacy accredited by an accrediting agency approved by the Secretary, or its equivalent, and who

serves on a full-time or part-time basis, as the activity of the service requires;

(2) staffed by a sufficient number of competent personnel, consistent with the residential facility's needs, and including—

(A) pharmacists necessary to provide comprehensive pharmacy services;

(B) technicians and clerical personnel to relieve the pharmacist of nonprofessional and clerical duties;

(3) pharmacists should have had training or experience in providing services to the mentally retarded and other individuals with developmental disabilities, and should be sensitive to their needs; and

(4) all pharmacists shall be familiar with, and adhere to, the code of ethics of the nationally recognized professional pharmaceutical association.

(o) Appropriate to the size of the residential facility, there should be a staff development program, designed to maintain and improve the skills of its pharmacy staff through means, including but not limited to:

(1) staff meetings and inservice training;

(2) seminars, workshops, conferences, and institutes;

(3) college and university courses;

(4) participation in professional organizations;

(5) participation in interdisciplinary groups;

(6) visits to other residential facilities; and

(7) access to relevant professional literature.

(p) The pharmacy serving the residential facility shall—

(1) have sufficient space for necessary compounding, dispensing, labeling, and packaging functions;

(2) have the equipment necessary for compounding, dispensing, issuing, storing, and administrative functions;

(3) be clean and orderly; and

(4) contain current pharmaceutical reference material to provide adequate information concerning drugs.

(q) Space for the storage of drugs in the storeroom, pharmacy, and living units shall be sufficient to prevent crowding of the drugs. There shall be adequate drug preparation areas, that are—

(1) properly secured;

(2) well lighted; and

(3) located so that personnel will not be interrupted when handling drugs.

(r) If the residential facility operates its own pharmacy, there should be—

(1) an office for the pharmacist; and

(2) a private area for instructing and counseling residents or parents on the correct use of drugs.

Subchapter IX—Physical and Occupational Therapy Services

Sec. 264. (a) Although this subchapter combines standards for physical and occupational therapy, each is a discrete service that complements the other in a manner similar to their relationship with all other health and medically related services. Both services, therefore, shall be provided, or made available to, residents on a continuing basis, as needed. Physical and occupational therapy services shall be provided in order to—

(1) prevent abnormal development and further disability;

(2) facilitate the optimal development of each resident; and

(3) enable the resident to be a contributing and participating member of the community in which he resides.

The residential facility shall have a written statement of its physical therapy and occupational therapy objectives for its residents, consistent with—

(1) the needs of the residents;

(2) currently accepted physical therapy and occupational therapy theories, principles, and goals;

(3) the philosophy and goals of the residential facility; and

(4) the services and resources provided.

Physical and occupational therapy services shall be provided—

(1) directly, through personal contact between therapists and residents;

(2) indirectly, through contact between therapists and other persons involved with the residents, to:

(A) create and maintain an atmosphere that recognizes the physical and psychosocial needs of residents and is conducive to the development and maintenance of optimal physical and psychological functioning;

(B) maximize the effectiveness of all programs for residents, through the application of knowledge concerning the development and maintenance of motor performance and behaviors; and

(C) implement programs for the improvement of physical and psychosocial functioning in all environmental settings.

Physical and occupational therapists shall have a responsibility for organizing and implementing programs to achieve physical and occupational therapy goals throughout the resident's daily activities.

(b) Physical and occupational therapy services available to the residential facility should include—

(1) screening and evaluation of residents;

(2) therapy with individuals and groups;

(3) program development services, including those relating to—

(A) resident habilitation;

(B) inservice training of professional, direct-care, and other staff;

(C) community participation;

(4) consultation with, or relating to—

(A) residents;

(B) families of residents;

(C) medical, dental, psychological, educational, nursing, and other services;

(D) the administration and operation of the residential facility;

(E) the community served by the residential facility;

(5) training of therapy staff;

(6) training of physical and occupational therapy graduate or undergraduate students, interns, supportive staff, and volunteer workers;

(7) assessment of program effectiveness; and

(8) conduct of, or participation in, research, and dissemination and appropriate application of research findings.

(c) Therapists should screen residents, in order to—

(1) determine the characteristics of the residential facility's population;

(2) identify resident needs and establish program priorities; and

(3) determine the administrative, budgetary, and personnel requirements of the service.

(d) Evaluation of individual residents by physical and occupational therapists should include—

(1) observing and testing performance and motivation in sensorimotor, perceptual, behavioral, and self-care activities;

(2) assessment and analysis of findings, to determine level of function and to identify deviations from accepted norms;

(3) providing information for interdisciplinary staff use, in determining diagnosis, functional capacities, prognosis, and management goals; and

(4) physical and occupational therapists shall participate, when appropriate, in the continuing interdisciplinary evaluation of individual residents, for the

purposes of initiation, monitoring, and followup of individualized habilitation programs.

(e) Physical therapy and occupational therapy staff shall provide treatment-training programs that are designed to—

(1) preserve and improve abilities for independent function, such as range of motion, strength, tolerance, coordination, and activities of daily living;

(2) prevent, insofar as possible, irreducible or progressive disabilities, through means such as the use of orthotic and prosthetic appliances, assistive and adaptive devices, positioning, behavior adaptations, and sensory stimulation;

(3) the therapist shall function closely with the resident's primary physician and with other medical specialists;

(4) treatment-training progress shall be—

(A) recorded regularly;

(B) evaluated periodically; and

(C) used as the basis for continuation or change of the resident's program.

(f) Evaluation results; treatment objectives, plans, and procedures; and continuing observations of treatment progress shall be—

(1) recorded accurately, summarized meaningfully, and communicated effectively;

(2) effectively used in evaluating progress; and

(3) included in the resident's unit record.

(g) Consumers and their representatives, including residents, families, other disciplines, and community groups, shall be utilized in the planning and evaluation of physical therapy and occupational therapy services. There shall be available sufficient, appropriately qualified staff, and supporting personnel, to carry out the various physical and occupational therapy services, in accordance with stated goals and objectives. Physical and occupational therapists shall be—

(1) graduates of a curriculum accredited by the appropriate nationally recognized association;

(2) if a physical therapist, eligible to practice in the State in which the residential facility is located; and

(3) if an occupational therapist, eligible for registration by the appropriate nationally recognized association.

(h) A physical therapist and an occupational therapist shall be designated as being responsible for maintaining standards of professional and ethical practice in the rendering of their respective therapy services in the residential facility. Each such therapist shall be qualified as required by the provisions of subsection (g) and, in addition, shall—

(1) have had 3 years of professional experience, 2 years of which should have been in working with the mentally retarded and other individuals with developmental disabilities;

(2) have demonstrated competence in administration and supervision, as appropriate to the residential facility's program; and

(3) preferably have a master's degree, in an area related to the program.

(i) Therapy assistants shall—

(1) be certified by the nationally recognized professional occupational therapy association or be graduates of a program accredited by the nationally recognized professional physical therapy association; and

(2) work under the supervision of a qualified therapist.

(j) Therapy aides shall—

(1) be provided specific inservice training; and

(2) work under the supervision of a qualified therapist or therapy assistant.

(k) Physical and occupational therapy personnel shall be—

(1) assigned responsibilities in accordance with their qualifications;

(2) delegated authority commensurate with their responsibilities; and

(3) provided appropriate professional direction and consultation.

(l) Physical and occupational therapy personnel shall be familiar with, and adhere to, the ethical codes and standards of practice promulgated by their respective nationally recognized professional organizations.

(m) Physical therapy and occupational therapy services operated by a residential facility shall seek consultation, at periodic intervals, from experts in physical therapy and occupational therapy who are not directly associated with the residential facility. Appropriate to the nature and size of the residential facility and to the physical and occupational therapy services, there shall be a staff development program that is designed to maintain and improve the skills of physical and occupational therapy personnel, through methods, including but not limited to:

(1) regular staff meetings;

(2) an organized inservice training program in physical and occupational therapy;

(3) visits to and from the staff of other residential facilities and programs;

(4) participation in interdisciplinary meetings;

(5) provision for financial assistance and time for attending professional conferences;

(6) provisions for encouraging continuing education, including educational leave, financial assistance, and accommodation work schedules;

(7) career ladders and other incentives to staff recruitment and development;

(8) workshops and seminars;

(9) consultations with specialists; and

(10) access to adequate library resources, which include current and relevant books and journals in physical and occupational therapy, mental retardation, development disabilities, and related professions and fields.

(n) Space, residential facilities, equipment, supplies, and resources shall be adequate for providing efficient and effective physical and occupational therapy services, including, but not necessarily limited to—

(1) residential facilities for conducting administrative aspects of the program;

(2) residential facilities for conducting screenings and evaluations;

(3) residential facilities for providing treatment and training for individuals and groups;

(4) such other space, staff, and services as are essential to support and maintain effective programs; and

(5) appropriate physical and occupational therapy consultation shall be employed in the design, modification, and furnishing of all physical and occupational therapy areas and residential facilities required to meet the specific goals of physical and occupational therapy services.

Subchapter X—Psychological Services

SEC. 265. (a) Psychological services shall be provided, in order to facilitate, through the application of psychological principles, techniques, and skills, the optimal development of each resident. Psychological services shall be rendered—

(1) directly, through personal contact between psychologists and residents;

(2) indirectly, through contact between psychologists and other persons involved with the residents, designed to—

(A) maintain an atmosphere that recognizes the psychological needs of residents and that is conducive to the development and maintenance of constructive interpersonal relationships; and

(B) maximize the effectiveness of all programs for residents, through the application of knowledge concerning the understanding and change of behavior.

(b) Psychological services available to the residential facility should include but not be limited to:

(1) evaluation and assessment of individuals and programs;

(2) therapy with individuals and groups;

(3) program development services, including those relating to—

(A) resident habilitation;

(B) staff training;

(C) community participation;

(D) resident, staff, and community motivation;

(4) consultation with, or relating to—

(A) residents;

(B) parents of residents;

(C) the administration and operation of the residential facility;

(D) the community served by the residential facility;

(5) psychology staff training; and

(6) conduct of research, consultation on research design, and dissemination of research findings.

(c) Psychologists shall participate, when appropriate, in the continuing interdisciplinary evaluation of individual residents, for the purposes of initiation, monitoring, and followup of individualized habilitation programs—

(1) psychologists shall conduct evaluations necessary to—

(A) meet legal requirements;

(B) meet research needs; and

(C) provide data for biostatistical reporting;

(2) methods of data collection employed in evaluation and assessment shall include, as appropriate—

(A) standardized tests and techniques;

(B) observations in natural and experimental settings, using standardized or generally accepted techniques;

(C) interviews with—

(i) the resident (or prospective resident);

(ii) members of the resident's family and other informants; and

(D) review of all pertinent records, including the comparison of current and previous status;

(3) collation, analysis, and interpretation of data shall—

(A) be performed in accordance with standards generally acceptable in professional psychology;

(B) provide, as appropriate, both intra- and interindividual comparisons, by reference to normative data; and

(C) utilize appropriate equipment, which is made available for the purpose;

(4) the reporting and dissemination of evaluation results shall be done in such a manner as to—

(A) render the content of the report meaningful and useful to its intended recipient and user;

(B) enhance clinical understanding of the individual;

(C) promptly provide information useful to staff working directly with the resident;

(D) facilitate use of data for research and professional education;

(E) facilitate use of data for statistical reporting; and

(F) maintain accepted standards of confidentiality;

(5) there shall be developed and maintained for each resident a continuing evaluation record that is frequently updated and that includes, but is not limited to, psychometric data.

(d) Psychologists shall participate, when appropriate, in the development of written, detailed, specific, and individualized habilitation program plans that—

(1) provide for periodic review, followup, and updating;

(2) are designed to maximize each resident's development and acquisition of—

(A) perceptual skills;

(B) sensorimotor skills;

(C) self-help skills;

(D) communication skills;

(E) social skills;

(F) self direction;

(G) emotional stability;

(H) effective use of time (including leisure time);

(I) basic knowledge;

(J) vocational-occupational skills; and

(K) socioeconomic values relevant to the community in which he lives.

(e) Psychologists should provide individual, or groups of, residents with therapy designed to develop, modify, and maintain behavior and attitudes that are rewarding and effective in meeting the demands of their intrapersonal and interpersonal situations. Psychologists should provide consultation and training services to program staff concerning:

(1) principles and methods of understanding and changing behavior, to the end of devising maximally effective programs for residents;

(2) principles and methods of individual and program evaluation, for the purposes of assessing resident response to programs and of measuring program effectivenes;

(3) psychologists should participate in the development of incentive systems designed to maximize motivation and to optimize, by means of provision for feedback, performance, and learning on the part of—

(A) residents enrolled in habilitation programs;

(B) staff engaged in resident habilitation programs; and

(C) personnel involved in resident habilitation resources in the community.

(f) Psychologists should provide assistance or consultation relative to—

(1) developing and conducting evaluations designed to select and maintain appropriate and effective staff;

(2) developing job analyses;

(3) psychological problems of staff, including the making of appropriate referrals;

(4) data concerning staff, and reports of evaluations of staff, shall—

(A) be provided in appropriate form, and only to clearly appropriate supervisory staff;

(B) enable data to be used for classification and reporting purposes;

(C) enable data to be used for research purposes; and

(D) maintain acceptable standards of confidentiality.

(g) Psychologists should participate in—

(1) educating appropriate members of the community, concerning the domiciliary, vocational, and recreational needs of residents who return to the community;

(2) planning with community officials the adaptation of domiciliary, vocational, and recreational resources, to optimize resident adjustments; and

(3) developing appropriate expectancies and attitudes within the community into which residents go.

(h) There shall be available sufficient, appropriately qualified staff, and necessary supporting personnel, to carry out the various psychological service activities, in accordance with the needs of the following functions:

(1) psychological services to residents, including evaluation, consultation, therapy, and program development;

(2) administration and supervision of psychological services;

(3) staff training;

(4) research;

(5) the residential facility should have available to it the services of at least one doctoral-level psychologist who is—

(A) a diplomate of the nationally recognized board of professional psychology, or is licensed or certified by a State examining board, or is certified by a voluntary board established by a qualified State professional psychological association;

(B) knowledgeable and experienced in the area of mental retardation or developmental disabilities;

(6) a psychologist, qualified as specified in subsection (h) (5) shall be designated as being responsible for maintaining standards of professional and ethical practice in the rendering of psychological services in the residential facility;

(7) all psychologists providing service to the residential facility shall—

(A) possess the educational and experiential qualifications required for membership in the nationally recognized professional psychological association;

(B) have demonstrated knowledge in the area of mental retardation and developmental disabilities;

(8) all psychological technicians, assistants, and clerks employed by the residential facility shall work under the direct supervision of a psychologist who is qualified as specified in subsection (h) (5);

(9) all members of the psychological services staff shall have and be familiar with, the ethical standards of psychologists and the nationally recognized casebook on ethical standards of psychologists, published by the nationally recognized appropriate professional psychological association, and all shall adhere to the ethical standards stated therein;

(A) all new psychology service employees shall receive this material, and be familiarized with it, as a part of their orientation; and

(B) the application of the ethical standards to practice with the mentally retarded and developmentally disabled in residential facilities shall be emphasized.

(i) Appropriate to the size of the residential facility, an ongoing inservice training program shall be conducted that is designed to maintain and improve the skills of its psychology staff, through methods, including but not limited to—

(1) staff seminars;

(2) outside speakers;

(3) visits to and from the staff of other residential facilities;

(4) attendance at conferences;

(5) participation in interdisciplinary groups;

(6) informational exchanges with universities, teaching hospitals, community mental health and mental retardation centers, and other community resources; and

(7) adequate library resources, including current and relevant books and journals in psychology and mental retardation and developmental disabilities shall be available.

(j) The training of interns and graduate students in psychology shall be encouraged, and appropriate supervision shall be provided. There shall be appropriate space and equipment for psychological services, including—

(1) offices for professional and clerical staff;

(2) testing and observation rooms;

(3) interviewing, counseling, and training and treatment rooms;

(4) play therapy rooms;

(5) access to conference rooms; and

(6) access to research and data analysis facilities.

Subchapter XI—Recreation Services

SEC. 266. (a) Recreation services should provide each resident with a program of activities that—

(1) promotes physical and mental health;

(2) promotes optimal sensorimotor, cognitive, affective, and social development;

(3) encourages movement from dependent to independent and interdependent functioning; and

(4) provides for the enjoyable use of leisure time.

(b) The residential facility shall have a written statement of its recreation objectives for residents, consistent with—

(1) the needs of its residents;

(2) currently accepted recreation principles and goals;

(3) the philosophy and goals of the residential facility; and

(4) the services and resources the residential facility offers.

(c) Recreation services available to the residential facility should include—

(1) recreation activities for the residents;

(2) recreation counseling;

(3) individual and group instruction of residents in recreation skills, to achieve maximum proficiency and develop leadership potential;

(4) therapeutic recreation;

(5) education and consultation; and

(6) research and evaluation.

(d) Recreation activities available to the residents should include, as appropriate to the size and location of the residential facility, and as adapted to the needs of the residents being served—

(1) excursions, outings, and other trips to familiarize the residents with community facilities;

(2) spectator activities, such as movies, television, sports events, and theater;

(3) participation in music, drama, and dance, such as rhythmics, folk dancing, community sings, group music sessions in the living units, performance in music or dramatic productions, performance in choral or instrumental groups, and informal listening to records or tapes;

(4) outdoor and nature experiences, including activities such as camping, hiking, and gardening;

(5) team sports and lead-up activities;

(6) individual and dual sports, such as bowling, archery, badminton, horseshoes, miniature golf, bicycling, and shuffleboard;

(7) hobbies, such as collecting, photography, model building, woodworking (including use of power tools), cooking, and sewing;

(8) social activities, such as clubs, special interest and discussion groups, social dancing, cookouts, parties, and games;

(9) service clubs and organizations, such as leaders clubs, scouting, 4-H, Junior Red Cross, Junior Chamber of Commerce, Hi-Y, Tri-Hi-Y, resident councils, and senior citizens clubs;

(10) aquatics, including waterplay, swimming, and boating;

(11) arts and crafts, including a wide range of activities from simple to complex, from reproductive to creative, and consistent with activities found in the community;

(12) physical fitness activities designed to develop efficient cardiovascular and cardiorespiratory functions,

strength, endurance, power, coordination, and agility, sufficient for both usual and extra demands;

(13) library services for reading, listening, and viewing, such as looking at books, listening to records and tapes, and viewing film strips and slides;

(14) celebration of special events, such as holidays and field days;

(15) winter activities, including snow sculpture snowplay, games, and sports;

(16) opportunities to use leisure time in activities of the resident's own choosing in an informal setting under minimal supervision, such as a "drop-in center";

(17) frequent coeducational experiences, to promote acceptable social behavior and enjoyment of social relationships; and

(18) activities for the nonambulatory, including the mobile and nonmobile.

(e) Maximum use should be made of all community recreation resources. Recreation counseling should be a continuous process that provides for—

(1) modification of resident's recreation behaviors;

(2) guidance to residents on how to find, reach, and utilize community recreation resources;

(3) family counseling in relation to recreation activities; and

(4) interpretation of residents' needs and abilities to community agencies.

(f) Therapeutic recreation, defined as purposive intervention, through recreation activities, to modify, ameliorate, or reinforce specific physical, emotional, or social behaviors, should include, as appropriate—

(1) participation on an interdisciplinary team, to identify the habilitation needs and goals of the resident;

(2) determination of appropriate recreation intervention, to achieve the stated habilitation goals;

(3) a written plan for implementing the therapeutic recreation objectives, consistent with the recommendations of the evaluation team; and

(4) evaluation of the effectiveness of such interventions, and subsequent redefinition of the resident's habilitation needs and goals.

(g) Education and consultation services should include—

(1) provision of stimulation, leadership, and assistance with recreation activities, conducted by the direct-care staff;

(2) staff training and development;

(3) orientation and training of volunteers;

(4) training of interns and students in recreation;

(5) consultation to community agencies and organizations, to stimulate the development and improvement of recreation services for the retarded and other developmentally disabled individuals; and

(6) public education and information, to encourage acceptance of the retarded and other developmentally disabled individuals in recreation activities.

(h) Recreational service shall be coordinated with other services and programs provided the residents, in order to make fullest possible use of the residential facility's resources and to maximize benefits to the residents. Activities in health, music, art, and physical education shall be coordinated with recreation activities relevant to these areas.

(i) Records concerning residents should include—

(1) periodic surveys of their recreation interests;

(2) periodic surveys of their attitudes and opinions regarding recreation services;

(3) the extent and level of each resident's participation in the activities program;

(4) progress reports, as appropriate;

(5) reports on relationships among peers, and between residents and staff; and

(6) evaluations conducted by personnel at all levels and, where appropriate, by staff from other services.

(j) Established procedures for evaluating and researching the effectiveness of recreation services, in relation to stated purposes, goals, and objectives, should include—

(1) utilization of adequate records concerning residents' interests, attitudes, opinions, participations, and achievements;

(2) time schedules for evaluation that are appropriate to the service or program being evaluated;

(3) provision for using evaluation results in program planning and development;

(4) provision for disseminating evaluation results in professional journals and in public education and information programs; and

(5) encouragement of recreation staff to initiate, conduct, and participate in research studies, under the supervision of qualified personnel.

(k) There shall be sufficient, appropriately qualified recreation staff, and necessary supporting staff, to carry out the various recreation services in accordance with stated goals and objectives.

(1) Scheduling of staff shall provide—

(A) coverage on evenings, weekends, and holidays; and

(B) additional coverage during periods of peak activity.

(2) Recreation personnel shall be—

(A) assigned responsibilities in accordance with their qualifications;

(B) delegated authority commensurate with their responsibility; and

(C) provided appropriate professional recreation supervision.

(3) Personnel conducting activities in recreation program areas should possess the following minimum educational and experiential qualifications:

(A) a bachelor's degree in recreation, or in a specialty area, such as art, music, or physical education; or

(B) an associate degree in recreation and one year of experience in recreation; or

(C) a high school diploma, or an equivalency certificate; and 2 years of experience in recreation, or 1 year of experience in recreation plus completion of comprehensive inservice training in recreation; or

(D) demonstrated proficiency and experience in conducting activities in one or more program areas.

(4) Personnel performing recreation counseling or therapeutic recreation functions should possess the following minimum education and experiential qualifications, and should be eligible for registration with the appropriate na-

tionally recognized therapeutic recreation society at the appropriate therapeutic recreation specialist level:

(A) a master's degree in therapeutic recreation and 1 year of experience in a recreation program serving disabled persons; or

(B) a master's degree in recreation and 2 years of experience in a recreation program serving disabled persons; or

(C) a bachelor's degree in recreation and 3 years of experience in a recreation program serving disabled persons; or

(D) a combination of education and experience in recreation serving disabled persons that totals 6 years.

(5) Education and consultation functions in recreation should be conducted by staff members, in accordance with their education, experience, and role in the recreation program.

(l) Appropriate to the size of the recreation program, there shall be a staff development program that provides opportunities for professional development, including—

(1) regular staff meetings;

(2) an organized inservice training program in recreation;

(3) access to professional journals, books, and other literature in the fields of recreation, therapeutic recrea-

tion, rehabilitation, special education, and other allied professions;

(4) provisions for financial assistance and time for attendance at professional conferences and meetings;

(5) procedures for encouraging continuing education, including educational leaves, direct financial assistance, and rearrangement of work schedules;

(6) provision for workshops and seminars relating to recreation, planned by the recreation and other professional and administrative staff; and

(7) provision for staff consultation with specialists, as needed, to improve recreation services to residents.

(m) Recreation areas and facilities shall be designed and constructed or modified so as to—

(1) permit all recreation services to be carried out to the fullest possible extent in pleasant and functional surroundings;

(2) be easily accessible to all residents, regardless of their disabilities;

(3) appropriate recreation consultation shall be employed in the design or modification of all recreation areas and facilities;

(4) toilet facilities, appropriately equipped in accordance with the needs of the residents, should be easily accessible from recreation areas; and

(5) appropriate and necessary maintenance services shall be provided for all recreation areas and facilities.

(n) Indoor recreation facilities should include, as appropriate to the residential facility—

(1) a multipurpose room;

(2) a quiet browsing room;

(3) access to a gymnasium;

(4) access to an auditorium;

(5) access to suitable library facilities;

(6) access to kitchen facilities;

(7) adequate and convenient space for storage of supplies and large and small equipment; and

(8) adequate office space for the recreation staff.

(o) Outdoor recreation facilities should include, as appropriate to the residential facility—

(1) access to a hard-top, all-weather-surface area;

(2) access to gardening and nature activity areas;

(3) access to adequately equipped recreation areas; and

(4) the residential facility's residents should have, as appropriate and feasible, access to year-round swimming and aquatic facilities.

(p) Adequate transportation services for recreation programs shall be provided. Recreation equipment and supplies in sufficient quantity and variety shall be provided to carry out the stated objectives of the activities programs. Toys, games, and equipment shall be—

(1) selected on the basis of suitability, safety, durability, and multiplicity of use; and

(2) adapted as necessary to the special needs of the residents.

(q) If a music therapy program is provided, it should include—

(1) participation by the music therapist, when appropriate, on an interdisciplinary evaluation team to identify the resident's needs and ways of meeting them;

(2) determination of music therapy goals for the resident and development of a written plan for achieving them;

(3) periodic progress reports, reevaluations, and program changes as indicated;

(4) direction by a therapist eligible for registration with the appropriate nationally recognized association for music therapy; and

(5) appropriate space, facilities, and equipment, with special consideration of the acoustical characteristics of rooms used for performing and listening.

Subchapter XII—Religious Services

SEC. 267. (a) Religious services shall be made available to residents, in accordance with their needs, desires, capabilities, and in accordance with their basic right to freedom of religion, in order to—

(1) develop and enhance their dignity;

(2) provide for the most meaningful and relevant practice of their religion; and

(3) provide spiritual programs designed to aid their development and growth as persons.

(b) Implementation of religious services should utilize community resources, whenever and wherever this is possible and be in the best interests of the residents. The objectives of the residential facility's religious services for it residents shall be directed toward full integration into, and membership in, their faith, and should include—

(1) upholding the dignity and worth of the individual;

(2) building moral and ethical standards of behavior;

(3) preparing for religious growth in their faith groups;

(4) establishing healthy self, world, and God concepts;

(5) establishing constructive value systems;

(6) giving direction toward greater personal maturity;

(7) strengthening interpersonal relationships; and

(8) contributing to growth in personal adequacy and happiness.

(c) Religious services shall be made available to all residents, regardless of their degree of retardation or developmental disability. Participation in religious programs shall be voluntary, in accordance with the wishes of the resident, if he or she expresses them, or with the wishes of his or her parent or guardian.

(d) Religious services to residents should include—

(1) worship opportunities, sacraments, and religious rites, according to the needs and abilities of the residents and consonant with the practices of their respective faiths;

(2) religious education programs geared to the needs and abilities of the residents;

(3) observation of dietary practices in keeping with the religious requirements of residents' faith groups;

(4) observation of religious holidays and holy days in keeping with the religious requirements of residents' faith groups;

(5) pastoral counseling, both individual and group, to residents and their families;

(6) pastoral visits to residents, with special emphasis on the care of the troubled, the sick, and the dying;

(7) pastoral consultation with persons concerned with the resident's welfare; and

(8) referral and communication between religious workers in the residential facility and in the community.

(e) Those who serve the religious needs of the residents, including clergy, religious educators, and volunteers, should whenever possible—

(1) assert and safeguard the full human and civil rights of the residents;

(2) participate, as appropriate, in team and other interdisciplinary planning regarding programs for individual residents, as well as in residential facility-wide or community programs;

(3) keep appropriate records of significant religious events in the lives of each resident;

(4) participate in training programs for residential facility personnel, including orientation of direct-care personnel in how they may help to further the religious programs for residents;

(5) participate in training programs for community clergy, theological students, and others;

(6) become involved with community clergy, and with religious and other groups, in their concerns for the spiritual care of the retarded and other developmentally disabled individuals;

(7) promote public understanding and acceptance of the retarded and other developmentally disabled individuals; and

(8) participate in their own faith group meetings, as required to maintain their standing.

(f) There shall be available sufficient, appropriately qualified personnel, which may include clergy or religious leaders, religious educators, volunteers, and clerical and supporting personnel, to carry out the various religious programs—

(1) religious services to residents shall be under the direction of a person who, in keeping with the size and nature of the residential facility, may be one of the following:

(A) a chaplain certified for work with the mentally retarded or other individuals with developmental disabilities by a recognized certifying agency;

(B) a clergyman or religious leader in good standing in his religious body;

(C) a religious educator; or

(D) a responsible person, who secures the services of qualified persons in carrying out the worship and education aspects of the program;

(2) chaplains serving residential facilities for the retarded, on a full- or part-time basis, should—

(A) be clergymen or religious leaders in good standing in their religious bodies; or

(B) be endorsed or assigned by their recognized religious bodies; or

(C) have B.A. and B.D. degrees, or their equivalents; and

(D) be certified for work with the mentally retarded or other individuals with developmental disabilities by a recognized certifying agency;

(3) professional religious educators serving residential facilities for the retarded or other individuals with developmental disabilities, on a full- or part-time basis, should—

(A) be endorsed or assigned by their recognized religious bodies; or

(B) have a bachelor's degree, or its equivalent; and

(C) be certified for work with the mentally retarded or other individuals with developmental disabilities by a recognized certifying agency;

(4) nonprofessional religious services personnel, including volunteers, should—

(A) be screened for ability to perform their assigned duties;

(B) be oriented to, and trained for, their assignments; and

(C) be provided ongoing supervision by a clergyman, religious leader, or religious educator of the respective faith.

(g) Appropriate to the size of the residential facility, there shall be an educational program designed to enhance the competencies of religious services personnel, through means such as:

(1) staff meetings and inservice training;

(2) seminars, workshops, conferences, and institutes;

(3) college and university courses;

(4) participation in professional organizations;

(5) participation in interdisciplinary groups;

(6) visits to other residential facilities;

(7) access to relevant professional literature; and

(8) religious services personnel should have access to qualified and appropriate consultation, as needed.

(h) Religious services personnel should be encouraged, when possible, to involve themselves in activities such as—

(1) offering clinical pastoral educational programs;

(2) providing educational experiences for students;

(3) developing innovative religious education materials;

(4) developing innovative worship services;

(5) conducting specific research and development projects; and

(6) exploring and expanding citizen advocacy programs.

(i) Residents shall have access to places appropriate for worship and religious education that are adequate to meet the needs of all. Religious services personnel shall be provided with office and other space, equipment, and supplies adequate to carry out an effective program.

Subchapter XIII—Social Services

SEC. 268. (a) Social services shall be available to all residents and their families, in order to foster and facilitate—

(1) maximum personal and social development of the resident;

(2) positive family functioning; and

(3) effective and satisfying social and community relationships.

(b) Social services shall be provided, directly and indirectly, to—

(1) the resident;

(2) his or her family;

(3) individuals or groups who represent different aspects of the social environment of the resident; and

(4) the community.

(c) Consumers and their representatives, including residents, families, other disciplines, and community groups shall participate in the planning and evaluation of social service programs. Social services, as part of an interdisciplinary spectrum of services, shall be provided through the use of social work methods directed toward—

(1) maximizing the social functioning of the resident;

(2) his or her family;

(3) modifying environmental influences leading to or aggravating, mental retardation or developmental disabilities;

(4) increasing public understanding and acceptance of mental retardation or developmental disabilities and its associated problems;

(5) creating a favorable climate to assist each retarded person to achieve as nearly normal living as is possible for the resident;

(6) asserting and safeguarding the human and civil rights of the retarded and other individuals with developmental disabilities and their families; and

(7) fostering the human dignity and personal worth of each resident.

(d) Social services available to the residential facility should include, as appropriate—

(1) preadmission evaluation and counseling, with referral to, and use of, other community resources, as appropriate;

(2) psychosocial assessment of the individual resident and his or her environment, as a basis for formulating an individual treatment plan;

(3) implementation of an individual social work treatment plan for the resident and his or her family;

(4) planning for community placement, discharge, and followup;

(5) participation in policy and program development within the residential facility in relation to—

(A) the resident's psychosocial needs and development;

(B) serving the families of the resident;

(C) use of community supportive and habilitative services;

(D) staff training and development;

(6) consultation with, or in relation to—

(A) programs offered by other disciplines;

(B) administration and operation of the residential facility;

(C) agencies and individuals in the community served by the residential facility;

(7) collaboration with other service delivery systems in planning and implementing programs for residents; and

(8) participation in social work and interdisciplinary program evaluation and research.

(e) During the evaluation process, which may or may not lead to admission, the resident and his or her family should be helped by social workers to—

(1) know the rights and services to which they are entitled, including the means of directing their appeals to the proper sources;

(2) obtain advocacy on their behalf if rights and services are denied them; and

(3) consider alternative services, based on the retarded or developmentally disabled person's status and salient family and community factors, and make a responsible choice as to whether and when residential placement is indicated.

(f) During the preadmission process, the resident and his or her family should be helped by social workers to—

(1) cope with problems of separation inherent in placement;

(2) initiate planning for the resident's return to his or her family or community;

(3) begin involving themselves as partners with the residential facility staff in developing a treatment and habilitation plan;

(4) become oriented to the practices and procedures of the residential facility; and

(5) share information about themselves that will provide the residential facility's staff with maximum understanding of their situation, so that effective services can be delivered.

(g) Social workers shall participate, when appropriate, in the continuing interdisciplinary evaluation of individual residents for the purposes of initiation, monitoring, and followup of individualized habilitation programs.

(h) During the retarded or developmentally disabled person's admission to, and residence in, the residential facility, or while he or she is receiving services from the residential facility, social workers shall provide liaison between him, the residential facility, the family, and the community, so as to:

(1) help the resident to—

(A) cope with problems accompanying separation from family and community;

(B) learn the roles and use the resources that will enable him or her to maximize his or her development;

(C) participate in programs, in accordance with his or her individual treatment plan, that will maximize his or her ability for independent living, in or out of the residential facility;

(2) help the staff to—

(A) individualize and understand the needs of the resident and his or her family in relation to each other;

(B) understand social factors in the resident's day-to-day behavior, including staff-resident relationships;

(C) prepare the resident for changes in his or her living situations;

(3) help the family to develop constructive and personally meaningful ways to support the resident's experience in the residential facility through—

(A) counseling concerned with problems associated with changes in family structure and functioning;

(B) utilization of the family's and the resident's own strengths and resources;

(C) referral to specific services, as appropriate; and

(4) the family to participate in planning for the resident's return to home or other community placement.

(i) After the resident leaves the residential facility, social workers shall provide systematic followup, including—

(1) counseling with the resident;

(2) counseling with family, employers, and other persons significant to the resident's adjustment in the community; and

(3) referral to appropriate community agencies.

(j) Social services shall help to integrate residential and other community services, through—

(1) providing liaison between the residential facility and the community;

(2) providing consultation to community agencies to facilitate the identification of needed resources for the retarded and other individuals with developmental disabilities and his family;

(3) interpreting the residential facility and its program to relevant sectors of the community;

(4) collaborating with other disciplines to help the community develop appropriate resources; and

(5) involvement with social policy issues that affect the retarded and other individuals with developmental disabilities.

(k) Social services shall develop and maintain comprehensive, current records, useful for its own programs and those of other services. There shall be available sufficient, appropriately qualified staff and necessary supporting personnel to carry out the various social service activities.

(1) The residential facility should have available to it a social worker who—

(A) has a master's or doctoral degree from an accredited school of social work;

(B) has had 3 years of post-master's experience in the field of social welfare;

(C) meets the educational and experiential qualifications for certification by the appropriate nationally recognized academy of certified social workers; and

(D) is knowledgeable and experienced in mental retardation.

(2) A social worker having the qualifications specified in subsection (k) (1) shall be designated as being responsible for maintaining standards of professional practice in the rendering of social services to the residential facility, and for staff development.

(3) Social workers providing service to the residential facility shall—

(A) have a master's degree from an accredited school of social works; or

(B) meet the educational qualifications required for full membership in the appropriate nationally recognized professional association of social workers and shall have had 3 years of experience in the field of social welfare.

(4) Social work assistants or aides employed by the residential facility shall work under the supervision of a social worker having the qualifications specified in subsection (k) (3).

(5) Social service personnel, at all levels of experience and competence, shall be—

(A) assigned responsibilities in accordance with their qualifications;

(B) delegated authority commensurate with their responsibilities; and

(C) provided appropriate professional social work supervision.

(6) A full-time supervisor should be responsible for the direct supervision of not more than six staff members, plus related activities.

(7) All social service personnel shall be familiar with, and adhere to, the code of ethics of appropriate nationally recognized professional associations.

(l) Appropriate to the size of the residential facility's social service program, an ongoing program of staff development shall be provided to improve the skills of the social work staff through such means as—

(1) inservice training;

(2) affiliation with schools of social work;

(3) staff consultation with specialists, as needed, to improve social services to residents;

(4) conference attendance, and other educational opportunities and forms of professional exchange; and

(5) career ladders and other incentives to staff recruitment and development.

(m) Space, facilities, equipment, supplies, and resources shall be adequate for providing effective social services, including—

(1) offices for social service and clerical staff;

(2) private interviewing rooms;

(3) rooms suitable for conferences and group activities;

(4) dictating and transcribing equipment;

(5) telephone service;

(6) travel provisions;

(7) provision for recordkeeping and information retrieval; and

(8) library services.

Subchapter XIV—Speech and Pathology and Audiology Services

SEC. 269. (a) Speech pathology and audiology services shall be available, in order to—

(1) maximize the communication skills of all residents; and

(2) provide for the evaluation, counseling, treatment, and rehabilitation of those residents with speech, hearing or language handicaps.

(b) The specific goals of speech pathology and audiology services shall be—

(1) appropriate to the needs of the residents served;

(2) consistent with the philosophy and goals of the residential facility;

(3) consistent with the services and resources offered by the residential facility; and

(4) known to, and coordinated with, other services provided by the residential facility.

(c) Speech pathology and audiology services shall be rendered through—

(1) direct contact between speech pathologists and audiologists and residents;

(2) participation with administrative personnel in designing and maintaining social and physical environments that maximize the communication development of the residents; and

(3) working with other personnel, such as teachers and direct-care staff, in implementing communication improvement programs in environmental settings.

(d) Speech pathology and audiology services available to the residential facility shall include, as appropriate—

(1) audiometric screening of—

(A) all new residents;

(B) children under the age of ten, at annual intervals;

(C) other residents at regular intervals;

(D) any resident referred;

(2) speech and language screening of—

(A) all new residents;

(B) children under the age of ten at annual intervals;

(C) all residents, as needed;

(3) comprehensive audiological assessment of residents, as indicated by screening results, to include tests of pure-tone air and bone conduction, speech audiometry, and other procedures, as necessary, and to include assessment of the use of visual cues;

(4) assessment of the use of amplification;

(5) provision of procurement, maintenance, and replacement of hearing aids, as specified by a qualified audiologist;

(6) comprehensive speech and language evaluation of residents, as indicated by screening results, including appraisal of articulation, voice, rhythm, and language;

(7) participation in the continuing interdisciplinary evaluation of individual residents for purposes of initiation, monitoring, and followup of individualized habilitation programs;

(8) treatment services, interpreted as an extension of the evaluation process, that include—

(A) direct counseling with residents;

(B) speech and language development and stimulation through daily living activities;

(C) consultation with classroom teachers for speech improvement and speech education activities;

(D) direct contact with residents to carry on programs designed to meet individual needs in comprehension (for example, speech reading, auditory training, and hearing aid utilization) as well as expression (for example, improvement in articulation, voice, rhythm, and language);

(E) collaboration with appropriate educators and librarians to develop specialized programs for developing the communication skills of multiple handicapped residents, such as the deaf, retarded, and the cerebral palsied;

(9) consultation with administrative staff regarding the planning of environments that facilitate communication development among residents in—

(A) living areas;

(B) dining areas;

(C) educational areas;

(D) other areas, where relevant;

(10) participation in inservice training programs for direct-care and other staff;

(11) training of speech pathology and audiology staff;

(12) training of speech pathology and audiology graduate or undergraduate students, interns, supportive staff, and volunteer workers;

(13) consultation with, or relating to—

(A) residents (for example, self-referral);

(B) parents of residents;

(C) medical (otological, pediatric, and so forth), dental, psychological, educational, and other services;

(D) the administration and operation of the residential facility;

(E) the community served by the residential facility; and

(14) program evaluation and research.

(e) Comprehensive evaluations in speech pathology and audiology shall consider the total person and his environment. Such evaluations should—

(1) present a complete appraisal of the resident's communication skills;

(2) evidence concern for, and evaluation of, conditions extending beyond observed speech, language, and hearing defects;

(3) consider factors in the history and environment relevant to the origins and maintenance of the disability;

(4) consider the effect of the disability upon the individual and the adjustments he makes to the problem as he or she perceives it; and

(5) consider the reaction of the resident's family, associates, and peers to the speech or hearing problem.

(f) Evaluation and assessment results shall be reported accurately and systematically, and in such manner as to—

(1) define the problem to provide a basis for formulating treatment objectives and procedures;

(2) render the report meaningful and useful to its intended recipient and user;

(3) where appropriate, provide information useful to other staff working directly with the resident;

(4) conform to acceptable professional standards, provide for intraindividual and interindividual comparisons, and facilitate the use of data for research and professional education; and

(5) provide evaluative and summary reports for inclusion in the resident's unit record.

(g) Treatment objectives, plans, and procedures shall—

(1) be based upon adequate evaluation and assessment;

(2) be based upon a clear rationale;

(3) reflect consideration of the objectives of the resident's total habilitation program;

(4) be stated in terms that permit the progress of the individual to be assessed;

(5) provide for periodic evaluation of the resident's response to treatment and of treatment effectiveness;

(6) provide for revision of objectives and procedures as indicated; and

(7) provide for assistance or consultation when necessary.

(h) Continuing observations of treatment progress shall be—

(1) recorded accurately, summarized meaningfully, and communicated effectively; and

(2) effectively utilized in evaluating progress.

(i) There shall be established procedures for evaluating and researching the effectiveness of speech pathology and audiology services, including but not limited to:

(1) utilization of adequate records concerning residents' response and progress;

(2) time schedules for evaluation that are appropriate to the service being evaluated;

(3) provision for using evaluation results in program planning and development;

(4) encouragement of speech pathology and audiology staff to participate in research activities; and

(5) provision for dissemination of research results in professional journals.

(j) There shall be available sufficient, appropriately qualified staff, and necessary supporting personnel, to carry out the various speech pathology and audiology services, in accordance with stated goals and objectives—

(1) A speech pathologist or audiologist, who is qualified as specified in paragraph (2) of this subsection, and who, in addition, has had at least 3 years of professional experience, shall be designated as being responsible for maintaining standards of professional and ethical practice in the rendering of speech pathology and audiology services in the facility.

(2) Staff who assume independent responsibilities for clinical services shall possess the educational and experiential qualifications required for the appropriate certificate of clinical competence issued by the appropriate nationally recognized professional speech and hearing association in the area (speech pathology or audiology) in which they provide services.

(3) Staff not qualified for such association certification shall be provided adequate, direct, active, and continuing supervision by staff qualified for certification in the area in which supervision is rendered.

(A) Supervising staff shall be responsible for the services rendered by uncertified staff under their supervision.

(B) Adequate, direct, and continuing supervision shall be provided nonprofessionals, volunteers, or other supportive personnel utilized in providing clinical services.

(4) Students in training and staff fulfilling experience requirements for such appropriate nationally recognized professional speech and hearing association certification shall receive direct supervision, in accordance with the requirements of the appropriate nationally recognized professional boards of examiners in speech pathology and audiology.

(5) All speech pathology and audiology staff shall be familiar with, and adhere to, the code of ethics published by the appropriate nationally recognized professional speech and hearing association.

(k) Appropriate to the nature and size of the residential facility and to the speech pathology and audiology service, there shall be a staff development program that is designed to maintain and improve the skills of speech pathology and audiology staff, through methods, including but not limited to—

(1) regular staff meetings;

(2) an organized inservice training program in speech pathology and audiology;

(3) visits to and from the staff of other residential facilities and programs;

(4) participation in interdisciplinary meetings;

(5) provision for financial assistance and time for attendance at professional conferences;

(6) provisions for encouraging continuing education, including educational leave, financial assistance, and accommodation of work schedules;

(7) workshops and seminars;

(8) consultations with specialists; and

(9) access to adequate library resources, which include current and relevant books and journals in speech pathology and audiology, mental retardation, and related professions and fields.

(l) Space, facilities, equipment, and supplies shall be adequate for providing efficient and effective speech pathology and audiology services, in accordance with stated objectives, including—

(1) adequate and convenient evaluation, treatment, counseling, and waiting rooms;

(2) specially constructed and sound-treated suites for audiological services, meeting appropriate standards;

(3) design and location such as to be easily accessible to all residents, regardless of disability;

(4) specialized equipment needed by the speech pathologist;

(5) specialized equipment needed by the audiologist, including an audiometer, with provisions for sound field audiometry, and equipment capable of performing at least the following procedures; hearing

screening, pure-tone air and bone conduction with contralateral masking, speech audiometry, site-of-lesion battery, nonorganic hearing loss battery, and hearing aid evaluation;

(6) provisions for adequate maintenance of all areas, facilities, and equipment, including—

(A) electroacoustic calibration of audiometers at regular, at least quarterly, intervals;

(B) calibration logs on all audiometers; and

(7) appropriate speech pathology and audiology consultation shall be employed in the design, modification, and equipage of all speech pathology and audiology areas and facilities.

Subchapter XV—Vocational Rehabilitation Services

SEC. 270. (a) The residential facility shall provide all its residents with habilitation or rehabilitation services, which includes the establishment, maintenance, and implementation of those programs that will insure the optimal development or restoration of each resident, physically, psychologically, socially, and vocationally—

(1) The residential facility shall have a written, public statement of its rehabilitation objectives for its residents, consistent with—

(A) the needs of its residents;

(B) currently accepted rehabilitation principles and goals;

(C) the residential facility's philosophy and goals; and

(D) the services and resources the residential facility offers.

(2) While the habilitation and rehabilitation concept and process embrace all efforts to achieve the optimal development of each resident, specific habilitation and rehabilitation services shall focus on the maximum achievement of—

(A) self-help skills;

(B) social competence, including communication skills;

(C) vocational competence; and

(D) independent living.

(b) The ultimate objective of vocational rehabilitation services shall be to assist every resident to move as far as he or she can along the continuum from vocational afunction to remunerative employment and entry into the mainstream of society as an independent citizen and worker. Vocational rehabilitation services shall be rendered—

(1) directly, through personnel contact between vocational rehabilitation personnel and residents; and

(2) indirectly, through contact between vocational rehabilitation personnel and other persons working with residents, designed to enhance and facilitate the develop-

ment and maintenance of a rehabilitative environment.

(c) Vocational rehabilitation services available to the residents, in accordance with their needs, shall include—

(1) vocational evaluation;

(2) the formulation of written vocational objectives for each resident;

(3) the formulation of a written plan to achieve the stated objectives;

(4) implementation of the vocational plan through—

(A) individual counseling;

(B) prevocational programs;

(C) vocational training;

(D) vocational placement;

(E) referral to appropriate sources for other services; and

(F) followup.

(d) Vocational evaluation of each resident shall—

(1) be initiated within one month after admission to the residential facility;

(2) arise out of a written comprehensive interdisciplinary evaluation (medical, psychological, social, and educational) that generates data relevant to vocational objectives and goals, such as information concerning—

(A) aptitudes and abilities;

(B) self-help and independent living skills;

(C) interests;

(D) self and vocational perception;

(E) sensorimotor coordination;

(F) communication skills;

(G) current social adjustment;

(H) educational history; and

(I) vocational and avocational history;

(3) be adequate for the formulation of vocational goals and of a detailed plan for the achievement of such goals;

(4) be adequate for the assessment of current vocational status and for the prediction of possible future status; and

(5) provide for periodic, but at least semiannual reevaluation, consistent with the progress of the resident toward the stated goals.

(e) The written vocational plan for each resident shall—

(1) be consistent with the vocational evaluation;

(2) specify the program to be undertaken to achieve his or her vocational objectives;

(3) indicate the order in which the program is to be undertaken;

(4) provide for the implementation of the evaluation team's recommendations; and

(5) assign the responsibility to carry out the plan.

(f) The resident shall be fully involved in his or her vocational evaluation, and in the formulation of his or her program plan. Prevocational services shall contribute to the development of work readiness in the resident, and shall provide—

(1) vocationally relevant academic instruction;

(2) instruction in the self-help and social skills necessary for vocational success;

(3) instruction and practice in the social skills necessary for maximally independent functioning in the community, such as travel, handling of money, and use of community resources;

(4) an orientation to the world of work;

(5) development of work attitudes needed for vocational success;

(6) rotated exploration and try-out of job tasks;

(7) continuous evaluation of vocational potential; and

(8) any necessary supportive services, including physical and mental restoration.

(g) Vocational training programs shall meet all applicable legal requirements, and shall be provided through means such as:

(1) work training stations;

(2) work activity centers;

(3) transitional sheltered workshops;

(4) work-study programs;

(5) on-the-job training;

(6) trade training, in the classroom or on the job;

(7) vocational training programs shall—

(A) provide for an evaluation of training progress at least every 3 months;

(B) make maximum use of job training resources—

(i) within the residential facility;

(ii) within the community;

(8) residential facilities conducting vocational training programs shall have vocational training personnel assigned, in such numbers and for such times as are necessary and appropriate to the situation, to supervise the training in each training area; and

(9) written, detailed training guides and curricula shall be available for all vocational training areas.

(h) Job placement services shall assist the individual to enter into appropriate kinds of employment, such as:

(1) competitive, remunerative employment;

(2) trade training programs;

(3) transitional or extended sheltered workshops;

(4) sheltered employment;

(5) homebound employment;

(6) homemaker; and

(7) in conjunction with job placement services, the individual shall be provided assistance related to off-the-job needs, activities, and resources, such as—

(A) living arrangements;

(B) social and recreation activities;

(C) medical services;

(D) educational resources;

(E) religious activities;

(F) transportation;

(G) legal affairs;

(H) financial affairs; and

(I) counseling.

(i) Systematic follow-up services shall be provided that—

(1) continue to be available to the individual for at least 1 year following placement;

(2) involve contact with—

(A) the individual;

(B) the individual's family or family-substitute; and

(C) the individual's employer, if appropriate;

(3) generate data concerning vocational outcomes to evaluate and improve the effectiveness of vocational rehabilitation programs.

(j) There shall be a clearly designated person or team responsible for the implementation, evaluation, and revision of the residential facility's vocational rehabilitation program.

(1) There shall be available to each resident in a vocational rehabilitation program a counselor who is responsible for seeing that the resident's vocational rehabilitation program is effectively carried out.

(2) A vocational rehabilitation counselor shall—

(A) have a master's degree in rehabilitation counseling, or a master's degree in a related area plus training and skill in the vocational rehabilitation process; or

(B) have a bachelor's degree and work under the direct supervision of a person described in (A).

(3) Vocational rehabilitation personnel providing training to residents in vocational areas shall be—

(A) vocational instructors certified by the appropriate State agency; or

(B) tradesmen who have attained at least journeyman status.

(k) Appropriate to the nature and size of the residential facility, provisions shall be made for vocational rehabilitation staff developments, through such means as—

(1) inservice training;

(2) short-term workshops;

(3) seminars;

(4) attendance at conferences; and

(5) visits to other residential facilities.

(l) Every residential facility that has a vocational rehabilitation program shall seek to establish working relationships with public and private rehabilitation agencies in the community. Each residential facility should have working relationships with university training programs in rehabilitation, including provision for—

(1) research opportunities;

(2) practical experiences;

(3) internship; and

(4) consultation.

Subchapter XVI—Volunteer Services

SEC. 271. (a) Volunteer services shall be provided in order to enhance opportunities for the fullest realization of the potential of each resident by—

(1) increasing the amount, and improving the quality, of services and programs; and

(2) facilitating positive relationships between the residential facility and the community which it serves.

(b) The residential facility shall have a written statement of the goals and objectives of its volunteer services program that are—

(1) appropriate to the needs of the residents;

(2) consistent with the philosophy and goals of the residential facility;

(3) developed in collaboration with the facility's staff;

(4) specific and measurable; and

(5) continuously assessed and periodically revised.

(c) Volunteers shall provide services, which may be direct or indirect, that are based on resident needs, staff requests, and volunteer skills, and that enhance programs, develop social competence, and build self-esteem—

(1) volunteer services shall supplement, but shall not be used in lieu of, the services of paid employees;

(2) volunteer participation shall comply with State laws, such as those relating to labor and insurance;

(3) volunteer participation shall be open to persons of both sexes, and of all ages, races, creeds, and national origins; and

(4) volunteer services shall be available to all residents, regardless of age, ability, or handicaps.

(d) Direct services provided to residents by volunteers, as appropriate to the residential facility's program and in cooperation with its staff, may include, but are not limited to—

(1) physical, occupational, and music therapy assistance;

(2) psychological testing assistance;

(3) behavior modification and programed instruction assistance;

(4) teacher or classroom assistance;

(5) religious instruction;

(6) recreation and leisure time activities;

(7) social skills development;

(8) library services;

(9) nursing services;

(10) transportation and escort assistance;

(11) visits, vacations, and trips;

(12) job and home findings; and

(13) citizen advocacy.

(e) Indirect services provided by volunteers, as appropriate to the residential facility's program and in cooperation with its staff, may include, but are not limited to—

(1) conducting tours;

(2) clerical and laboratory assistance;

(3) gift shop and canteen operation;

(4) public relations and community education; and

(5) contributions.

(f) Volunteer services staff should provide the following services—

(1) to the residential facility's staff—

(A) orientation in the need for, and philosophy of volunteer services;

(B) identification of how and where volunteers can be utilized; and

(C) assistance in developing training for volunteers;

(2) to the volunteers—

(A) orientation, training, and placement;

(B) opportunities to participate in planning and evaluating their experiences; and

(C) appropriate recognition of their services and contributions.

(g) Volunteer services staff functions shall include—

(1) development and implementation of a plan for recruitment, selection, deployment, orientation, training, supervision, evaluation, recognition, advancement, and separation of volunteers;

(2) development in collaboration with appropriate staff, of job descriptions for volunteers;

(3) maintenance of complete and accurate records, including, but not necessarily limited to—

(A) hours of volunteer service rendered;

(B) individuals and organizations providing services;

(C) materials and moneys received; and

(D) operational budget.

(h) The staff members responsible for residential facility programs utilizing volunteers shall be responsible providing such volunteers with on-the-job training, supervision, and consultation.

(i) The cooperation and involvement of staff and community, which is essential to a successful volunteer services program, should be achieved by means such as—

(1) a standing staff committee on volunteer services, to foster communications and cooperation, to evaluate and coordinate existing programs, and to stimulate new programs;

(2) a volunteer services advisory committee, composed of representatives of appropriate community organizations;

(3) encouragement of, and involvement with parents groups;

(4) collaboration with appropriate agencies and community groups; and

(5) recruiting volunteers representative of the community served by the residential facility, in respect of age, sex, socioeconomic, religious, racial, and ethnic groups.

(j) There shall be available sufficient, appropriately qualified staff, and necessary supporting personnel, to carry out the volunteer services program, in accordance with stated goals and objectives.

(1) A residential facility staff member shall be designated to be responsible and accountable for volunteer services—

(A) where the size of the residential facility and scope of the program warrant, the person responsible for volunteer services shall devote full time to this area;

(B) volunteer services shall be organized within the administrative structure of the residential facility in such a way as to be available to, and maximally utilized by, all relevant services and programs; therefore, the staff member responsible for volunteer services should report to an individual with residential facility-wide administrative responsibility; and

(C) the staff member responsible for volunteer services should have the same relationship to volunteers as a personnel officer has to paid employees.

(2) The staff member responsible for volunteer services shall have—

(A) the necessary interpersonal, consultative, leadership, and organizational and administrative skills and abilities;

(B) demonstrated ability to identify, mobilize, and deploy volunteer resources to meet the needs of residents;

(C) knowledge of community organization;

(D) knowledge of current practices and concepts in mental retardation and other developmental disabilities; and

(E) training or experience in organizing and administering volunteer services, as appropriate to the nature and size of the residential facility, and preferably—

(i) a baccalaureate degree in a behavioral science; and

(ii) 3 years of experience in volunteer services or related area.

(k) Appropriate to the size of the residential facility, there should be a staff development program designed to maintain and improve the skills of volunteer services staff, through means such as—

(1) seminars, workshops, and conferences;

(2) college and university courses;

(3) participation in professional organizations;

(4) participation in interdisciplinary groups;

(5) visits to other residential facilities; and

(6) access to relevant professional literature.

(l) There shall be adequate and accessible space, facilities, equipment, and supplies for providing efficient and effective volunteer services. If a canteen is operated by the residential facility, it shall—

(1) be operated for the benefit of the residents;

(2) be open to residents, staff, families, and visitors, without segregation by space or hours of use, so as to facilitate interaction;

(3) provide opportunities for residents to purchase items for their personal needs;

(4) provide opportunities for the training of residents; and

(5) be operated so that any profits derived are utilized for the benefit of residents.

Chapter 4.—RECORDS

Subchapter I—Maintenance of Residents' Records

Sec. 272. (a) A record shall be maintained for each resident that is adequate for—

(1) planning and continuous evaluating of the resident's habilitation program;

(2) providing a means of communication among all persons contributing to the resident's habilitation program;

(3) furnishing documentary evidence of the resident's progress and of his response to his habilitation program;

(4) serving as a basis for review, study, and evaluation of the overall programs provided by the residential facility for its residents;

(5) protecting the legal rights of the residents, residential facility, and staff; and

(6) providing data for use in research and education.

(b) All information pertinent to the above-stated purposes shall be incorporated in the resident's record, in sufficient detail to enable those persons involved in the resident's program to provide effective, continuing services. All entries in the resident's record shall be—

(1) legible;

(2) dated; and

(3) authenticated by the signature and identification of the individual making the entry.

(c) Symbols and abbreviations may be used in the record entries only if they are in a list approved by the residential facility's chief executive officer and a legend is provided to explain them. Diagnoses should be recorded in full and without the use of symbols or abbreviations.

Subchapter II—Content of Records

SEC. 273. (a) The following information should be obtained and entered in the resident's record at the time of admission to the residential facility:

(1) name, date of admission, date of birth, place of birth, citizenship status, marital status, and social security number;

(2) father's name and birthplace, mother's maiden name and birthplace, and parents' marital status;

(3) name and address of parents, legal guardian, or next of kin;

(4) sex, race, height, weight, color of hair, color of eyes, identifying marks, and recent photograph;

(5) reason for admission or referral problem;

(6) type and legal status of admission;

(7) legal competency status;

(8) language spoken or understood;

(9) sources of support, including social security, veterans' benefits, and insurance;

(10) provisions for clothing and other personal needs;

(11) information relevant to religious affiliation;

(12) reports of the preadmission evaluations; and

(13) reports of previous histories and evaluations.

(b) Within the period of one month after admission there shall be entered in the resident's record—

(1) a report of the review and updating of the preadmission evaluation;

(2) a statement of prognosis that can be used for programing and placement;

(3) a comprehensive evaluation and individual program plan, designed by an interdisciplinary team; and

(4) a diagnosis based on the appropriate nationally recognized professional association's manual on terminology and classification in mental retardation and other developmental disabilities and, where necessary, the diagnostic and statistical manual of mental disorders, most recent edition, published by the appropriate nationally recognized professional psychiatric association.

(c) Records during residence should include—

(1) reports of accidents, seizures, illnesses, and treatments thereof, and immunizations;

(2) record of all periods of restraint, with justification and authorization for each;

(3) report of regular, at least annual, review and evaluation of the program, developmental progress, and status of each resident;

(4) observations of the resident's response to his program, recorded with sufficient frequency to enable evaluation of its efficacy;

(5) record of significant behavior incidents;

(6) record of family visits and contacts;

(7) record of attendance and leaves;

(8) correspondence;

(9) periodic updating of the information recorded at the time of admission; and

(10) appropriate authorizations and consents.

(d) At the time of discharge from the residential facility, a discharge summary shall be prepared that should—

(1) include a brief recapitulation of findings, events, and progress during residence, diagnosis, prognosis, and recommendations and arrangements for future programing;

(2) be completed and entered in the resident's record within 7 days following discharge; and

(3) with the written consent of the resident or his guardian, be copied and sent to the individual or agency who will be responsible for future programing of the resident.

(e) In the event of death—

(1) a copy of the death certificate should be placed in the resident's record; and

(2) when a necropsy is performed, provisional anatomic diagnoses should be recorded within 72 hours, where feasible, and the complete protocol should be made part of the record within 3 months.

Subchapter III—Confidentiality of Records

SEC. 274. (a) All information contained in a resident's records, including information contained in an automated data bank, shall be considered privileged and confidential—

(1) the record is the property of the residential facility whose responsibility it is to secure the information against loss, defacement, tampering, or use by unauthorized persons;

(2) the record may be removed from the residential facility's jurisdiction and safekeeping only in accordance with a court order, subpena, or statute;

(3) there shall be written policies governing access to, duplication of, and dissemination of information from the record; and

(4) written consent of the resident or his guardian shall be required for the release of information to persons not otherwise authorized to receive it.

Subchapter IV—Central Record Service

SEC. 275. (a) The residential facility shall maintain an organized central record service for the collection and dissemination of information regarding residents. A centralized or decentralized system of recordkeeping may be used in accordance with the needs of the residential facility—

(1) there shall be a unit record that contains all information pertaining to an individual resident for all admissions to the residential facility;

(2) where particular professional services require the maintenance of separate records, a summary of the information contained therein shall be entered in the unit record at stated intervals;

(3) records shall be readily accessible to authorized personnel;

(4) where a centralized system is used, appropriate records shall also be available in the resident-living units; and

(5) a periodic review of the content of the records should be made by—

(A) record personnel, to assure that they are current and complete; and

(B) a committee of appropriate staff, including the record librarian, to assure that they meet the standards set forth in section 278;

(6) there shall be a master alphabetical index of all residents admitted to the residential facility; and

(7) records shall be retained for the period of time specified by the residential facility, but at least for the period of time consistent with the statute of limitations of the State in which the residential facility is located.

Subchapter V—Statistical Records

SEC. 276. (a) While the type and amount of statistical information will depend upon the residential facility's particular needs, such information should include at least the following:

(1) number of residents by age groups, sex, race, and place of residence;

(2) number of residents by level of retardation, according to the appropriate nationally recognized professional association on mental deficiency classification;

(3) number of residents by level of adaptive behavior, according to the appropriate nationally recognized professional association of mental deficiency classification;

(4) number of residents with physical disabilities;

(5) number of residents who are ambulatory and nonambulatory (mobile and nonmobile);

(6) number of residents with sensory defects;

(7) number of residents with convulsive disorders, grouped by level of seizure control;

(8) number of residents by etiological diagnoses, according to the appropriate nationally recognized professional association and, where necessary, the DSM-II classifications;

(9) movement of residents into, out of, and within the residential facility; and

(10) length of stay.

(b) Data shall be reported to appropriate Federal and other agencies as requested.

Subchapter VI—Records Personnel

SEC. 277. (a) There shall be available sufficient, appropriately qualified staff, and necessary supporting personnel, to facilitate the accurate processing, checking, indexing, filing, and prompt retrieval of records and record data.

(b) The record system should be supervised on a full- or part-time basis, according to the needs of the residential facility, by an individual who—

(1) is a registered record librarian; or

(2) is an accredited record technician; or

(3) has demonstrated competence and experience in administering and supervising the maintenance and use of records and reports.

(c) Record personnel should—

(1) be involved in educational programs relative to their activities, including orientation, on-the-job training, and regular inservice education programs; and

(2) participate in workshops, institutes, or correspondence education courses available outside the residential facility.

(d) There shall be adequate space, facilities, equipment, and supplies for providing efficient and effective record services.

Chapter 5.—RESEARCH

Subchapter I—Encouragement of Research

SEC. 278. (a) Recognizing that the understanding, prevention, and amelioration of mental retardation and other developmental disabilities ultimately depends upon knowledge gained through research, the administration and staff of the residential facility (and, in the case of public facilities, the appropriate governmental agency) shall encourage research activity.

(1) opportunities and resources should be made available to members of the staff who are equipped by interest and training to conduct applied or basic research. Research resources or necessary research assistance should be made available to all staff members who have identified researchable problems related to the programs for which they are responsible;

(2) research by qualified investigators who are not staff members of the residential facility shall be encouraged. There shall be a written policy concerning the conduct of research in the residential facility by investigators who are not staff members. Outside researchers shall fulfill the same obligations relative to staff information and feedback as do residential facility staff members. Consideration should be given to the assignment of a residential

facility staff member to each research project conducted by outside investigators; and

(3) where feasible, there shall be ongoing, cooperative programs of research and research training with colleges, universities, and research agencies.

(b) The administration of the residential facility shall make provision for the design and conduct, or the supervision, of research that will objectively evaluate the effectiveness of program components and contribute to informed decision-making in the residential facility.

Subchapter II—Review of Research Proposals

SEC. 279. (a) An interdisciplinary research committee shall review all proposed studies to insure—

(1) adequacy of research design, and

(2) implementation of ethical standards in the design.

(b) Residential facility staff members shall be consulted regarding the planning of research and the utilization of research findings in their areas of competence and interest.

Subchapter III—Conduct of Research

SEC. 280. (a) The residential facility shall follow, and comply with the statement of assurance on research involving human subjects required by the United States Department of Health, Education, and Welfare for projects supported by that agency or any appropriate more stringent such statement, as appropriate.

(b) Investigators and others directly involved in the research shall—

(1) adhere to the ethical standards of their professions concerning the conduct of research; and

(2) have access to the record of informed consent.

Subchapter IV—Reporting Research Results

SEC. 281. (a) The principal investigator of each research project shall be responsible for communicating to the staff of the residential facility the purpose, nature, outcome, and possible practical or theoretical implications of the research. Copies of the report resulting from research projects shall be maintained in the residential facility.

(b) Where research findings are made public, care shall be taken to assure the anonymity of individual residents and parents.

(c) Clearly defined mechanisms shall exist for informing staff members of new research findings that have applicability to the programs and administration of the residential facility. There shall be evidence that currently applicable research results are being implemented in the residential facility's programs.

Chapter 6.—SAFETY AND SANITATION

Subchapter I—Safety

SEC. 282. (a) The requirements of the Secretary shall be met, with specific reference to the following—

(1) provision of adequate and alternate exits and exit doors;

(2) provision of exit ramps, with nonskid surface and slope not exceeding one foot in twelve; and

(3) provision of handrails on stairways.

(b) There shall be records that document strict compliance with the regulation of the State or local fire safety authority that has primary jurisdiction over the residential facility—

(1) aisles and exits shall be free from all encumbrances and floors shall be uncluttered;

(2) flammable materials shall be properly stored and safeguarded;

(3) attics and basements shall be kept orderly and free of rubbish; and

(4) there shall be records of periodic fire safety inspections and reports.

(c) There shall be a written staff organization plan and detailed, written procedures, which are clearly communicated to, and periodically reviewed with staff, for meeting all potential emergencies and disasters pertinent to the area, such as fire, severe weather, and missing persons.

(1) The plans and procedures should include—

(A) plans for the assignment of personnel to specific tasks and responsibilities;

(B) instructions relating to the use of alarm systems and signals;

(C) information concerning methods of fire containment;

(D) systems for notification of appropriate persons;

(E) information concerning the location of fire-fighting equipment; and

(F) specification of evacuation routes and procedures.

(2) The plans and procedures shall be posted at suitable locations through the residential facility.

(d) Evacuation drills shall be held at least quarterly, for each shift of residential facility personnel and under varied conditions, in order to—

(1) insure that all personnel on all shifts are trained to perform assigned tasks;

(2) insure that all personnel on all shifts are familiar with the use of the firefighting equipment in the residential facility;

(3) evaluate the effectiveness of disaster plans and procedures;

(4) evacuation drills shall include actual evacuation of residents to safe areas during at least one drill each year, on each shift. There shall be special provisions for the evacuation of the physically handicapped, such as fire chutes and mattress loops with poles; and

(5) there shall be a written, filed report and evaluation of each evacuation drill.

(e) An active safety program shall be maintained by a multidisciplinary safety committee that investigates all accidents and makes recommendations for prevention. Records of the activities of the safety committee shall be kept. There shall be adequate safety shields on the moving parts of all dumbwaiters, elevators, and other machinery, as provided for in applicable standards and codes.

(f) All buildings and outdoor recreation facilities constructed after 1971 shall be accessible to, and usable by, the nonambulatory and shall meet standards of the Secretary for making building accessible to, and usable, by the physically handicapped—

(1) all existing buildings and outdoor recreation facilities shall be modified so as to conform to the above standards by December 31, 1976; and

(2) existing residential facilities shall provide—

(A) entrance ramps wide enough for wheelchairs, not exceeding a rise of one foot in twelve, with nonslip surfaces, and with rails on both sides;

(B) doorways and corridors wide enough for wheelchairs; and

(C) grab bars in toilet and bathing facilities.

(g) Paint used in the residential facility shall be lead free. Old paint or plaster containing lead shall have been removed, or covered in such manner that it is not accessible to residents.

(h) Appropriate provisions shall be made for emergency auxiliary heat by means of alternate sources of electric power, alternate fuels, or standby equipment.

Subchapter II—Sanitation

SEC. 283. (a) There shall be records that document strict compliance with the sanitation, health, and environmental safety codes of the State or local authorities having primary jurisdiction over the residential facility. Written reports of inspections by State or local health authorities, and records of action taken on their recommendations, shall be kept on file at the residential facility.

(b) The holding, transferring, and disposal of waste and garbage shall be done in a manner that will not create a nuisance, nor permit the transmission of disease, nor create a breeding place for insects or rodents—

(1) waste that is not disposed of by mechanical means shall be—

(A) kept in leakproof, nonabsorbent containers with close-fitting covers; and

(B) disposed of daily;

(2) containers shall be thoroughly cleaned inside and out, each time they are emptied; and

(3) impervious plastic liners should be used.

(c) Handwashing facilities shall be available in, or immediately adjacent to—

(1) bathrooms;

(2) toilet rooms;

(3) sleeping areas; and

(4) kitchens.

(d) There shall be adequate insect screens on all windows and doors where needed and adequate janitorial equipment and storage space in each unit of the residential facility.

Chapter 7.—ADMINISTRATIVE SUPPORT SERVICES

Subchapter I—Functions, Personnel, and Facilities

SEC. 284. (a) Adequate, modern administrative support shall be provided to efficiently meet the needs of, and contribute to, program services for residents, and to facilitate support of a variety of resources, which may include, but need not be limited to, the following kinds of services: clerical, communication, dietary, financial, housekeeping, laundry, personnel, physical plant, records, safety and security, and supply and purchasing.

(b) Administrative support functions should be directed by a qualified administrator, trained and experienced to provide skilled and efficient coordination of these services, to adequately meet the residential facility's program objectives. In larger residential facilities, provision may be made for both executive direction, via a chief executive officer (superintendent, director), and administration of support services (via a business manager). In smaller residential facilities, a single person may provide both program direction and administration of support services—

(1) the administrator of support services should—

(A) have at least a baccalaureate degree; or

(B) have completed formal graduate education in health administration or its equivalent;

(2) all administrative support personnel shall have sufficient understanding and appreciation of the nature and behavior of the mentally retarded and developmentally disabled resident, to assure that each employee's work and his or her relations to the residents contribute positively to their welfare.

(c) There shall be adequate office space, facilities, equipment, and supplies for the efficient conduct of all administrative support functions.

PART D—STANDARDS FOR COMMUNITY FACILITIES AND AGENCIES; PROGRAMS FOR MENTALLY RETARDED AND OTHER PERSONS WITH DEVELOPMENTAL DISABILITIES

Subpart 1—Individual Support Systems

CASE FINDING

SEC. 285. (a) For the purposes of this part the term "case finding" means the processes of systematically reaching into the community for the purposes of identifying persons in need of services provided pursuant to this title; alerting persons and their families to the availability of such services; locating providers of such services; and assisting persons to enter the service delivery system.

(b) Facilities and agencies receiving Federal assistance under this Act shall—

(1) establish written policies for its case finding program;

(2) designate a staff member to monitor and to follow up the case finding process;

(3) maintain evidence of its case finding activities in the following areas:

(A) identifying persons in need of services, locating services to meet their needs, and assisting them in entering the service delivery system;

(B) alerting relevant agencies and individuals of the importance of early detection, especially with high risk populations, and of their role as case finders;

(C) coordinating its case finding activities with the case finding activities of relevant agencies and practitioners; and

(D) reaching out to meet the expressed or unexpressed needs of the inarticulate.

ENTRY INTO THE SERVICE DELIVERY SYSTEM

SEC. 286. (a) "Entry", for purposes of this part, means actions taken by a facility or agency to bring a person in need of services into the service delivery system, and to the actions taken by such facility or agency immediately preceding and following actual entry.

(b) Facilities and agencies receiving assistance under this Act shall—

(1) establish written policies regarding its entry procedures, and stipulate in such policies that persons are accepted for entry services without regard to ethnic origin, sex, or ability to pay and without regard to the ability of the facility or agency to provide direct services;

(2) obtain, provide, or coordinate any services needed to facilitate entry, including assurances that—

(A) the facility's or agency's hours of operation shall be arranged to enable easy accessibility for total family units;

(B) staff members responsible for the entry interview shall be readily accessible;

(C) transportation shall be arranged, or a home visit made if necessary, for the initial interview;

(D) available sources of funding shall be identified for the person and his or her family;

(3) service, at the point of referral, any followup required to facilitate the person's entry into the service delivery system, and such facility or agency—

(A) shall obtain from the person and his or her family, and from other appropriate sources, the information needed to determine appropriate referrals;

(B) may use the recorded information to make appropriate referrals to other agencies; and

(C) shall have policies and procedures that define the conditions of discharge and procedures for reentry if needed;

(4) insure that the entry procedure shall be evaluated annually, and that such evaluation shall include maintenance of a log of requests for information, en-

tries, referrals, follow-up services, dispositions, and reasons for rejection, the data from which log shall be reviewed as a basis for planning, evaluating, and modifying the facility's or agency's role and as a part of the community coordinating process, that such data is shared with other agencies for use in planning, evaluating, and modifying the service delivery system in such a way that it does not reveal the identity of the individuals.

FOLLOW-ALONG SERVICES

SEC. 287. (a) "Follow-along" as used in this part means provision for a continuing relationship with the person and his or her family, which may extend over the life of the person, for the purpose of assuring that changing needs are recognized and appropriately met. The facility or agency which provided services to a person shall remain available as a contact for persons who are no longer receiving services but who seek support or guidance with respect to needs formerly accommodated by such facility or agency.

(b) Facilities and agencies receiving assistance under this Act shall—

(1) provide follow-along services to persons as needed;

(2) educate persons it serves to seek follow-along the services when such services are needed to enhance the independence of such persons; and

(3) provide to each person served specific point of contact within the facility or agency, in order to receive follow-along service.

(c) Each facility and agency, together with other appropriate facilities or agencies, shall identify each person's primary follow-along agency, in order to promote efficient service and reduce duplication of efforts. The person and his or her family shall be informed by the appropriate facility or agency of the procedures for terminating or reentering a follow-along service program. Such facility or agency shall insure that the follow-along service assists with the transition to a new service, as necessary; that the person's right to privacy is not violated; and that the person's status is recorded at least annually. A facility or agency providing follow-along service may have access to any appropriate information in the person's records.

INDIVIDUAL PROGRAM PLAN

SEC. 288. (a) The individual program plan is a written plan of intervention and action that is developed, and modified at frequent intervals, with the participation of all concerned. It shall specify objectives and goals, and identify a continuum of development, outlining projected progressive steps, and the developmental consequences of services.

(b) Facilities and agencies receiving assistance under this Act shall insure that—

(1) each person enrolled in a service has an individual program plan;

(2) the initial individual program plan is developed within five days after the person is enrolled in a service;

(3) the individual program plan includes, at a minimum, assessment data with respect to the person's sensorimotor development, communicative development, social development, affective development, and cognitive development;

(4) the objectives of the individual program plan are developed with the participation of the person, his or her family, all relevant agency staff members, and staff of other agencies involved in serving the client;

(5) each objective of the individual program plan are stated separately, sequenced within a time frame, and expressed in behavioral terms that provide measurable indices of progress;

(6) the individual program plan describes the conditions, activities, or barriers that interfere with the achievement of the objectives;

(7) the individual program plan specifies modes of intervention for the achievement of the stated objectives;

(8) the individual program plan identifies agencies capable of delivering the services required;

(9) the individual program plan identifies a designated focus of responsibility for utilizing and coordinating services provided by different practitioners or agencies;

(10) the individual program plan included day-to-day training activities designed to assist in attaining the stated objectives;

(11) the individual program plan is written in terms that are understandable to the person and his or her family;

(12) the individual program plan is reviewed at least quarterly in order to measure the person's progress, modify the objectives as necessary, determine the services that are needed, and provide guidance and remediation techniques to modify barriers to growth; and

(13) the individual program plan includes a written agreement that specifies the role and objectives of each party to the implementation of the individual program plan, and provides for at least semiannual review of the plan by all parties concerned.

PROGRAM COORDINATION

SEC. 289. (a) Program coordination is the process of establishing responsibility for implementation of the person's individual program plan. Such process includes providing support, procuring direct services, coordinating services, collecting and disseminating data and information, and monitoring the progress of the person.

(b) Facilities and agencies receiving assistance under this Act shall insure that—

(1) each person served by the agency is assigned a program coordinator responsible for implementing his or her individual program plan;

(2) the person and his or her family shall participate in the selection of the program coordinator, and that the program coordinator is identified to the person, to his or her family, and to appropriate staff members;

(3) the program coordinator attends to the total spectrum of the person's needs including, but not limited to housing, family relationships, social activities, education, finances, employment, health, recreation, and records;

(4) the program coordinator determines whether or not the person's needs are being met, and how the person's needs are being met;

(5) the program coordinator arranges supportive services for the person and his or her family, locates and procures services outside the agency when needed, and coordinates the delivery of all services to the person;

(6) in order to keep the individual program plan up to date the program coordinator secures relevant data from other agencies providing service;

(7) the program coordinator provides documentation relevant to the review of the individual program plan required by section 284;

(8) the program coordinator monitors the operation of the services that are provided to the person; and

(9) the program coordinator facilitates the transfer of the person to another service or agency when such transfer is determined to be appropriate.

PROTECTIVE SERVICES

SEC. 290. (a) Each State which receives assistance under this Act shall establish a system of continuing legal and social protection which shall monitor programs and assist persons in securing their rights under law, and their entitlements. Each such State shall provide advice and guidance to persons and, if necessary, actively intervene in social and legal processes.

(b) Each State providing protective services shall insure that—

(1) the protective services function shall be independent of any facility or agency providing direct services;

(2) the programs of each facility and agency are monitored and audited to an extent which assures the receipt by each person served of all of the benefits, services, and rights to which they are entitled;

(3) services are provided to persons in congregate living situations, as well as those living alone or in families;

(4) protective intervention is provided in cases of abuse or neglect of either children or adults;

(5) no right of a person protected pursuant to this section may be abridged without due process, which shall include—

(A) notice to the affected person, appropriate family members, and other interested persons advance of the proposed abridgement, and an explanation to the affected person and his or her family of the reason for such abridgement, his or her rights, with respect thereto, and the means for appeal from such abridgement;

(B) evaluation of the appropriateness of such abridgement by individuals professionally qualified to do so;

(C) the modification of the right shall be specific to the person's ability to exercise that right; and

(D) opportunity for judicial review.

(6) there is provision for periodic review of the need to abridge the right of any person, and for restoration of any right that is abridged, should the circumstances justify its restoration;

(7) each facility and agency shall participate in educating law enforcement agencies and the local bar association concerning the nature of mental retardation and other developmental disabilities, and the special needs of persons with such disabilities, and that each facility and agency shall make its resources available to law enforcement officials in the event that such persons are subjected to arrest, questioning, or detention;

(8) each facility and agency shall work with law enforcement officials and the courts in establishing a system for processing the developmentally disabled offender that provides recognition of diminished responsibility and a means for avoiding unnecessary or undue confinement; and

(9) each facility and agency shall instruct each person it serves concerning the law and how he or she may obtain assistance if arrested, and shall provide any such person who has communication problems, or who desire this service, with a means of identifying himself or herself to law enforcement officials.

PERSONAL ADVOCACY SERVICES

SEC. 291. (a) Personal advocacy services include the provision of competent individuals to assist mentally retarded and other developmentally disabled persons to cope with problems, including the exercise of their personal and legal rights.

(b) Each facility and agency providing personal advocacy services shall—

(1) identify persons needing personal advocates;

(2) select, recruit, and train volunteers as advocates;

(3) assess the ability of each volunteer to perform competently as an advocate;

(4) provide practical assistance to personal advocates, and secure any legal and professional services that may be needed by the advocate for the person;

(5) mediate the assumption of a legal role, such as guardian or adoptive parent, by a personal advocate;

(6) evaluate the performance of each advocate and the adequacy and effectiveness of the personal advocacy services program at least quarterly;

(7) have written procedures for terminating advocacy service at the request of either the advocate or the person;

(8) solicit recommendations of advocates and persons with respect to the expansion or modification of personal advocacy services;

(9) publicize the program to consumers, interested citizens, and cooperating agencies; and

(10) prepare and publish material for use in orienting and training personal advocates.

(c) (1) Each personal advocate assigned pursuant to this section shall monitor individual program plans for persons assigned to him for advocacy services.

Each such advocate shall be known to the client program coordinator and to the protective services worker assigned to the person.

(2) In accordance with the needs of the person, the personal advocate's functions and supportive social activities shall include, but are not limited to—

(A) providing companionship in activities of daily living;

(B) providing assistance in solving problems of daily living;

(C) supplying missing or needed affective relationships, as parent or sibling substitute, or as friend;

(D) working to increase the person's competency and independence;

(E) helping to obtain needed services; and

(F) challenging agency practices that appear to discriminate against the person.

(3) Each facility and agency shall coordinate its activities with personal advocacy services personnel to insure that the persons it serves receive personal advocacy services if

needed. If personal advocacy services are not otherwise available, the agency shall proceed to establish them.

GUARDIANSHIP SERVICES

SEC. 292. (a) Guardianship services are those services provided by a person in a public or private agency who is serving as a guardian when there is no suitable relative or friend available to assume this responsibility for the person receiving services.

(b) Each facility and agency assisted under this Act shall—

(1) assist the person, his or her family, and the court in determining the need for guardianship, including a determination of whether guardianship of either the person or the property or of both is needed, whether such guardianships should be combined or separate and, where State law provides for both plenary and limited guardianship, the appropriate level of guardianship;

(2) assist the person, his or her family, and the court in assuring that a qualified private individual or a qualified individual in a public or private agency is available as a guardian to such person, insuring that no individual or agency who is responsible for rendering a direct service to a person will also be appointed guardian of that person;

(3) if State law provides for corporate guardianship (guardianship by an organization rather than by an individual), assist in establishing procedures that will eliminate conflicts of interest;

(4) assist the guardian in understanding mental retardation and other developmental disabilities, and in fostering increased independence on the part of his or her ward;

(5) assist guardians to become more effective in securing the rights, benefits, and services for their wards' needs, and to which they are entitled; and

(6) the agency shall work with the client, his or her family, and the court to insure that all guardianship procedures provide for due process;

(c) (1) In those cases in which a guardian is compensated for his or her services, the facility or agency shall demonstrate its efforts to insure that such compensation is in accordance with actual duties performed, rather than based solely on the income or assets of the ward and that no person will be denied legal guardianship services due to inadequate resources.

(2) The agency shall assist the client, his or her family, and the court in assuring that timely and appropriate procedures are available for the orderly continuation or reestablishment of guardianship upon the

attainment of the age of majority, or for the person who otherwise needs continuation or reestablishment of guardianship, and, where appropriate, the appointment of a suitable successor guardian.

(3) The agency shall further assist the person, his or her family, and his attorney in the appropirate utilization of property management devices such as wills and trusts, educate the community concerning the need for and the availability of guardianship services, and if guardianship services are not available, the facility or agency shall establish one.

Subpart 2—Agency Service Components

PURPOSE

SEC. 293. (a) The program coordinator shall assist in the carrying out of the individual program plan by selective use of the direct services available. Each facility and agency that supplies one or more services shall publish a clear statement of the extent and limitations of the service or services that it provides. Such facility or agency shall demonstrate a willingness to modify its services in relation to the needs of the person and his or her family, in relation to other services, and in response to community planning processes.

(b) Each agency shall be evaluated on the basis of the specific component services that it provides. Each of the service components described in this subpart shall be available within the service delivery system of each State.

INDIVIDUAL ASSESSMENT

SEC. 294. (a) Individual assessment means an empirical process to determine if, and to what degree, a person has developmental deficiencies, and what interventions and services are needed to increase the independent functioning of such person. The individual assessment shall identify the present developmental level of the person, the conditions that impede his development, and, where possible, the etiology of the disability.

(b) Each facility and agency receiving assistance under this Act shall—

(1) provide or procure assessment services, identify for persons it serves and their families those areas in which it is competent to offer assessment services, and have written procedures for referring the person to other agencies for assessment services that it does not provide;

(2) include in each individual assessment, in order to provide data for the individual program plan, comprehensive assessments of sensorimotor, communicative, social, affective, and cognitive development;

(3) provide, through an interdisciplinary team constituted of members drawn from, or representing, such professions, disciplines, or service areas as are rele-

vant in each particular case, a comprehensive medical examination, dental evaluation, visual and auditory screening, speech and language screening, and psychological and social assessments, including specialized assessments, where needed;

(4) insure that all State licensure, certification, and registration laws regulating the professional disciplines authorized to perform specific diagnostic tests shall be observed;

(5) assign specific responsibility for synthesizing, interpreting, and utilizing the results of the assessment components provided by different practitioners or agencies;

(6) insure that the assessment process is adapted to the cultural background, language, and ethnic origin of the person and his or her family;

(7) insure that assessment data are recorded in terms that facilitate clear communication across disciplines and with persons;

(8) insure that each assessment identifies the symptomatology of problems or disabilities, and, where possible, their etiologies;

(9) insure that the assessment process identifies all available alternatives for the selection of needed services, establishes a focus of responsibility for those services,

and that such process involves the person and his or her family and that they are advised of the assessment findings;

(c) A preliminary individual assessment shall be completed within thirty days after entry. Reassessment shall be provided at developmental intervals during childhood, adolescence, and adulthood; provided at times of crisis; and available when behavioral responses indicate the need. Assessments reports may be sent to other facilities or agencies that provide services to the person and his or her family if written permission to do so is provided by such person or his or her family.

ATTENTION TO HEALTH NEEDS

SEC. 295. (a) Health needs include the needs for health care that are common to all persons, and any special health needs that arise from problems associated with mental retardation and other developmental disabilities.

(b) Each facility and agency receiving assistance under this Act shall—

(1) have identifiable procedures for the early detection and remediation of the special health needs of the person;

(2) provide or procure health assessments for each person served, including dental evaluations, at regular intervals, but at least annually;

(3) provide for the detection, diagnosis, and treatment of sensorimotor deficits;

(4) provide or procure corrective or prosthetic devices in accordance with specialists' recommendations, along with periodic reevaluation of corrective or prosthetic devices by appropriate professional personnel, to ascertain their continued applicability and fitness, and to recommend changes as needed, and instruction to parents and to pertinent staff members in the proper use and care of such devices;

(5) provide or procure home health services to foster implementation of the home aspects of the special health remediation program;

(6) insure that the special health needs of persons served are met by the generic resources of the community;

(7) provide that health supervision for disabled children shall conform to the regulations of the Secretary;

(8) provide nutritional services to assist in planning adequate and proper diets, including special diets when needed;

(9) provide services to develop functional oral systems such as sucking, swallowing and chewing;

(10) have written policy regarding the administration of all medications used by persons served, including those not specifically prescribed by the attending practitioner, except that no medication shall be administered to a person without a written order by a physician; and written policy specifying the procedures to be followed in medical emergencies, and in rendering emergency medical care;

(11) insure that each person who requires medication shall receive appropriate medical supervision, which includes regular evaluation of his or her response to the medication, with appropriate monitoring and laboratory assessment;

(12) have policies and procedures for persons with infectious and contagious diseases which conform to State and local health department regulations, and copies of such policies and procedures shall be available to all staff, persons served, and their families;

(13) include in its inservice training program instruction in the proper handling of persons with convulsive disorders, and insure that such instruction is given to all personnel who work with such persons;

(14) make available to persons served and their families specialized family planning services and genetic counseling services.

(c) Any facility or agency which does not provide specialized health services shall refer each person and his or her family to the appropriate agencies and follow up on such referrals.

ATTENTION TO DEVELOPMENTAL NEEDS

SEC. 296. (a) Attention to developmental needs means the provision of specific opportunities for growth and development.

(b) Effective programs for mentally retarded and other developmentally disabled persons shall be based upon a developmental model which assumes that (1) change and development begin at conception and continue throughout the life span of every human being, (2) human development progresses in a sequential, orderly, and predictable manner, (3) specific opportunities for development must be provided if development is to occur, and (4) the rate and direction of development are influenced by many factors, some of which can be significantly modified by utilizing and controlling certain physical, psychological, and social aspects of the environment. The objective of services which attend to developmental needs shall be to enhance development and increase adaptive behavior by modifying the rate and direction of behavioral change.

(c) Attention to developmental needs shall be made available by each facility and agency receiving assistance under this Act to every person served, regardless of age, or type or degree of disability. Programs shall be designed to (1) enable such persons to develop an increasing degree of control over his or her environment, and (2) to gradually produce more complex behavior patterns that increase the person's capacity to cope with his or her environment. The person's individual program plan must specify the progressive developmental steps and goals that are to be attained.

(d) Basic goals for development shall include understanding, appreciating, and caring for the natural world; promoting esthetic experiences and creating emotional stability; learning to perform work for reimbursement; and learning a critical or intellectual method by which to evaluate experiences and environment.

(e) The objectives of education and training programs shall be to maximize the person's development. Arbitrary time and age limits shall not be imposed on any process of education.

(f) Each facility and agency receiving assistance under this Act shall—

(1) assist in initiating developmental programs that begin in infancy and continue throughout the life-span;

(2) insure that its program is determined by individual developmental needs, and is not contingent on age or time restrictions;

(3) implement in each person's individual program plan the progressive developmental steps and goals that are to be attained;

(4) define the responsibilities of both the agency and the family as they affect individual attainment of developmental objectives, and the communication mechanism;

(5) provide or procure formal education and training services that begin with early childhood programs and continue through post-secondary schools and vocational training activities including opportunities for continuing education and retraining without arbitrary time and age limits, and which are directed toward integrating the person in the most appropriate learning environment that is available in the community;

(6) insure that the objectives of its education and training programs shall be related to the long-range goals of its clients, to include the achievement of academic knowledge and the development of competence in activities of daily living;

(7) insure that education and training programs meet the standards established by the appropriate State agency and that instructional techniques, physical settings, and materials are appropriate to the ages and developmental levels of each person served;

(8) identify programs and services available to the person and his or her family from other sources, to reinforce and enrich its education program;

(9) document the person's participation in the selection of alternatives relating to activities of daily living;

(10) prohibit the use of corporal punishment and verbal abuse (shouting, screaming, swearing, name calling, or any other activity that would be damaging to a person's self-respect) and seclusion (defined as the placement of a person alone in a locked room); and

(11) have a written policy that defines the use of behavior modification programs, the staff members who may authorize their use, and a mechanism for monitoring and controlling their use, in which

(A) noxious or aversive stimuli shall be employed only in very extreme situations and only when reviewed and approved by the agency's or facility's research and human rights committees, conducted with the consent of the client's family, and the use of such stimuli is described in written plans;

(B) medication shall not be used as punishment, for the convenience of staff, as a substitute for a program, or in quantities that interfere with a developmental program; and

(C) persons shall not discipline other persons, except as part of an organized self-government program that is conducted in accordance with written policy.

SENSORIMOTOR DEVELOPMENT

SEC. 297. (a) Motor development means the development of those behaviors that primarily involve muscular, neuromuscular, or physical skills, and varying degrees of physical dexterity. Sensory development includes the development of perceptual skills.

(b) Each facility and agency receiving assistance under this Act shall —

(1) include in each individual program plan objectives relating to sensorimotor development, including, but not limited to, the development of balance and posture, perceptual-motor skills, locomotor skills, manipulative skills, and body image; and shall evaluate and record each person's development at least quarterly;

(2) have specific programs directed to the sensorimotor development of nonambulatory individuals;

(3) have individually prescribed sensorimotor development activities performed by each person regularly, where appropriate, which are designed to increase individual skills, strength, and endurance, modified in

accordance with the person's progress toward his or her sensorimotor development objectives;

(4) provide direct services or obtain consulting services from professionally qualified persons to assist person and his or her family in sensorimotor training; and

(5) demonstrate functional integration of sensorimotor activities and therapeutic interventions in the educational, social, recreational, developmental, or vocational programs that it provides.

COMMUNICATIVE DEVELOPMENT

SEC. 298. (a) Communicative development means the development of communication skills, transmitting meaning to others, either verbally or nonverbally.

(b) Each facility and agency receiving assistance under this Act shall—

(1) include in each individual program plan objectives relating to communicative development, and the progress of the person toward these objectives shall be recorded at least quarterly;

(2) provide appropriate training in the areas of sensory stimulation, awareness, appropriate gestures, receptive skills, speaking, writing, reading, listening, and expression;

(3) provide specialized services or procure to correct structural or habit deficits that interfere with persons' communicative development;

(4) provide for each person specific opportunities for the use of functional communication skills in activities of daily living; and

(5) provide instruction concerning the availability and utilization of all forms of communication media, such as radio, television, telephone, and such specialized equipment as may be required.

SOCIAL DEVELOPMENT

SEC. 299. (a) Social development means the formation and growth of self-help and interpersonal skills that enable a person to establish and maintain appropriate roles and maintain fulfilling relationships within his or her environment.

(b) Each facility and agency receiving assistance under this Act shall—

(1) insure that each individual program plan contains objectives relating to social development, and that the progress of the person relative to these objectives shall be recorded at least quarterly;

(2) provide for the development of culturally normative behavior by persons it serves, including a sequential life education program, opportunities for social

development appropriate to the person's chronological age, and activities that promote the development of socially adaptive relationships with the opposite sex;

(3) provide activities for individual social interaction outside the training programs;

(4) provide programs to (A) assist the person with clothing selection and grooming appropriate to various social situations, such as work, school, church, and leisure time activities; and (B) as a part of the social development program, provide special training relating to safety in all activities of daily living;

(5) design a program for use by the person's family to encourage independent functioning through the acquisition of self-help and interpersonal skills;

(6) provide counsel for the person and his or her family concerning interpersonal conflicts, or conflicts arising from isolated or disorganized families, and if referral is made for counseling, it shall provide follow-up to insure resolution of the conflict.

AFFECTIVE DEVELOPMENT

SEC. 299A. (a) Affective development means the development of feelings and emotions, including behaviors that relate to, arise from, or influence, interests, attitudes, emotions, and values.

(b) Each facility and agency receiving assistance under this Act shall—

(1) include in each individual program plan objectives relating to affective development, and the progress of the person toward these objectives shall be recorded at least quarterly;

(2) develop, with the client and his or her family, a plan for developing the expression of appropriate emotional behaviors;

(3) provide a warm, accepting environment that is conducive to the development of positive feelings, including opportunities for the expression of appropriate feelings;

(4) provide for the development and enhancement of the person's self-concept through activities that promote awareness of self and the experience of success and security;

(5) provide a variety of experiences to develop the client's interest in and appreciation of the esthetic components of his environment; and

(6) provide specific training objectives for persons displaying maladaptive behavior that lead to more adaptive behavior, and maintain records of significant maladaptive behavior, and of actions taken by parents and staff as a consequence of such behavior, and, when

necessary, provide specialized therapeutic techniques to develop constructive adaptive behaviors.

COGNITIVE DEVELOPMENT

SEC. 299B. (a) Cognitive development means the development of those processes by which sensory input is transformed, stored, recovered, and used, including processes and abilities involved in perceiving, recognizing, remembering, conceiving, judging, reasoning, thinking, and knowing.

(b) Each facility and agency receiving assistance under this Act shall—

(1) include in each individual program plan objectives relating the cognitive development which are written in behavioral terms, and progress relative to these objectives shall be recorded at least quarterly;

(2) help parents to recognize and implement their roles in fostering the cognitive development of the child;

(3) provide initial activities in the development of cognitive skills at the most basic developmental level, including sensory stimulation;

(4) provide specialized services to remediate or compensate for specific barriers to learnings; and

(5) provide opportunities for alternatives leading to independent action, including evaluation of the consequences of the person's decisions.

SERVICES TO SUPPORT EMPLOYMENT AND WORK

SEC. 299C. Each person shall be prepared for opportunities to engage in productive work or other meaningful occupation that leads toward making an economic contribution to society and securing a decent standard of living.

(b) Each facility and agency receiving assistance under this Act shall—

(1) include work objectives in each individual program plan directed to maximizing the independence of the person, which are established in cooperation with the person, based on a recorded evaluation of work potential, and which include the attainment of at least partial employability or self-support, or other meaningful occupation;

(2) provide opportunities for, and assist the client in the selection of, alternatives in vocational training and retraining;

(3) integrate its work and employment programs with the community by providing or obtaining occupational training, adjunctive therapy, bio-engineering consultations, or other services that are designed to maximize the person's level of work functioning; establishing locations in the community where on-the-job training takes place; facilitating the placement of persons in full-time employment at the Federal minimum wage or

higher; providing or obtaining reimbursed work experiences for those persons whose evaluations document that they are unable to utilize or attain on-the-job training, full-time employment, or sheltered work in the community; and providing or obtaining follow along to insure that the employee has opportunity for job upgrading or reevaluation, in order to increase employment potential;

(4) provide the person with materials for productive work at his or her place of residence, when this is in his or her best interest;

(5) provide support to the person by helping him or her make constructive use of leisure time; assisting in the development of peer relationships in leisure time activities; and maximizing opportunities for increasingly independent living by minimizing the effects of the disability;

(6) maintain at least yearly contact with the advocate, guardian, family, or other responsible person to evaluate the work expectations and performance of the person;

(7) maintain documentary evidence of each person's production level earning rate;

(8) insure that persons who are paid for productive work shall be provided benefits that include, but are not limited to effective grievance procedures; provisions for

paid vacations, holidays, and sick leave; workmen's compensation; provisions for health insurance and retirement; opportunities for continuing educational activities; and provisions for recognizing outstanding contributions to the agency; and

(9) utilize definitive time study procedures and competitive bidding practices.

RECREATION AND LEISURE

SEC. 299D. (a) Recreation means the satisfying use of leisure time. Recreation and leisure activities may be elements of a person's daily life in which participation may be planned, requested, or self-initiated to meet a basic need and to provide personal enjoyment.

(b) Each facility and agency receiving assistance under this Act shall—

(1) provide or obtain recreation and leisure time activities that are designed to allow the person to choose whether or not to participate, and to choose the type of activity in which he or she wishes to participate; develop skills and interests leading to enjoyable and satisfying use of leisure time; provide opportunities to be successful; provide experiences that develop social interaction skills; provide activities that promote physical and emotional health; and provide individualized therapeutic

activities for the alleviation of disabilities and the prevention of regression;

(2) plan and organize recreation programs and activities to include a specific set of objectives for each person, based upon his or her individual program plan; assessments of the person's abilities and performance level, to determine the type of recreation activities that are appropriate; grouping of persons according to their expressed wishes and probable abilities; careful selection of the method of presentation, in accordance with the abilities of the participants; availability of and access to desired activities; communication and coordination with other agencies to develop wider opportunities in programing; opportunities to participate with nondisabled people; and parent and family education concerning leisure time activities;

(3) provide recreation activities to persons who are served by other agencies, and to others who are not served by any direct program, through daytime activities for children; after-school activities; after-work and evening activities; weekend activities; and summer activities;

(4) if generic, community recreation programs are not available to the disabled, initiate action with appropriate agencies in order to make such programs avail-

able, including consultation and training services to generic agencies in developing and implementing programs for persons served;

(5) insure that recreation programs are available to severely and multiple disabled persons; and

(6) keep the population that it serves informed of all recreation opportunities.

FAMILY RELATED SERVICES

SEC. 299E. (a) Family related services are those that specifically serve both the person and his or her family, to include a range of services provided both within and without the home by a variety of agencies and disciplines. The term also includes services for a disabled adult who is married and has a family.

(b) All services provided to persons under this Act shall include consideration and involvement of his or her family, and the special emotional, social, and educational needs of the family must be recognized. Family members shall be assisted to increase their understanding of the impact of disability, to improve their understanding of the person and their relationships with him or her, and to mobilize their own strengths in coping with the disability in a constructive fashion. Instruction in ways of facilitating the development of the person, including training in specific management techniques, shall be provided.

HOME TRAINING SERVICES

SEC. 299F. (a) Home training services means specialized services that are provided to a person and his or her family in the home setting, as an extension of his or her total program.

(b) Each facility and agency receiving assistance under this Act shall—

(1) provide home training services through a home trainer, who shall:

(A) develop with the family a developmentally sequenced management and training program that is a component of the individual program plan, and that is carried out in the home;

(B) instruct the family in how to carry out the program;

(C) provide for family use of specialized instructional material;

(D) provide information on developmental disabilities and developmental patterns;

(E) develop with the family a method of assessing the assets, liabilities, and level of performance of the person;

(F) assist the person and the family in incorporating the therapy offered by various disciplines into the daily regime;

(G) coordinate the person's activities with services delivered by others;

(H) demonstrate special procedures;

(I) help adapt home equipment;

(J) help the family make or identify resources for obtaining specialized equipment;

(K) assist the family with special clothing adaptations; and

(L) provide continuing support and assistance;

(2) coordinate its efforts with other agencies and services that are involved with the person and his or her family and if home training services are not available the facility or agency shall initiate such services.

HOMEMAKER SERVICES

SEC. 299G. (a) Homemaker services means services in caring for the family in the home during periods of need or crisis, and teaching family members techniques of home management.

(b) Each facility or agency receiving assistance under this Act shall insure that—

(1) homemaker services shall be available, when needed, to families with a disabled person living at home, and to disabled adults living in their own homes;

(2) the homemaker shall teach appropriate techniques of home management, including good health care, meal planning, marketing, budgeting, and housekeeping;

(3) the homemaker's home management skills shall be sufficient to meet a variety of family emergencies, including relief in a crisis;

(4) evaluation of the family's needs shall be made prior to the placement of a homemaker, and shall continue after the homemaker is in the home;

(5) the homemaker shall be apprised of the family situation prior to entering the home;

(6) the homemaker shall be prepared to assist with the training program of the person, so that he or she may remain in the home; and

(7) if homemaker services are not available, the agency shall initiate such services.

RESPITE CARE

SEC. 299H. (a) Respite care means short-term, out-of-the-home care of a person that is provided for the temporary relief of his or her family.

(b) Each facility and agency receiving assistance under this Act shall—

(1) provide day and night respite care services;

(2) identify to persons and their families other agencies that provide respite care;

(3) have a written plan for the retirement, selection, training, and evaluation of persons who provide respite care;

(4) monitor respite care services to insure continuity with the normal living patterns of those being served; and

(5) if respite care services are not available initiate such services.

SITTER SERVICES

SEC. 2991. (a) Sitter services means in-the-home care of a person for the temporary relief of his or her family.

(b) Each facility and agency receiving assistance under this Act shall—

(1) provide sitter services, available on an hourly or weekly schedule;

(2) have a written plan for the recruitment, selection, training, and evaluation of persons who provide sitter services;

(3) insure that sitter services personnel shall have specialized training and experience in the management of disabled persons;

(4) if the agency does not provide sitter services, identify sources for obtaining qualified sitter services; and

(5) if sitter services are not available, initiate such services.

FAMILY EDUCATION SERVICES

SEC. 229J. (a) Family education services means the provision of opportunities for the family to increase its knowledge and understanding of mental retardation and other developmental disabilities, and of other concerns relating to the family unit.

(b) Each facility and agency receiving assistance under this Act shall—

(1) provide family education opportunities on a regularly scheduled basis and as family needs arise, in which family members are involved in the development and evaluation of family education programs; and in which family education techniques shall be adapted to the cultural, educational, and economic characteristics of the families being served;

(2) insure that family members have an opportunity to observe the person in a service setting, establishing procedures by which these observations are discussed with the appropriate staff;

(3) insure that planned conferences between staff members and individual families are held on a regularly scheduled basis, as needs arise, and either in or out of the home, as appropriate;

(4) provide parent-to-parent counseling activities for newly identified parents and in times of crisis;

(5) conduct group meetings for siblings of persons who are disabled;

(6) maintain a resource library relating to mental retardation and other developmental disabilities, available for use by the family, which includes basic information on mental retardation and other development disabilities, information on developmental patterns, information on techniques of management and training, information relating to attitudes and feelings toward, and understanding of, the developmentally disabled, and instructional materials, including games and toys, and information on their use; and

(7) have a planned program for mobilizing and utilizing parent leadership skills.

ATTENTION TO NEEDS FOR MOBILITY

SEC. 299K. (a) Mobility means the ability of persons to move within, and thereby interact with, their environment. Attention to needs for mobility means helping nonambulatory persons to become mobile or partially mobile, as well as enabling them to use public and private transportation systems to meet their normal needs.

(b) Each facility and agency receiving assistance under this Act shall—

(1) provide services to increase the mobility of disabled persons as specified in their individual plans,

including services and equipment necessary to improve ambulation and to promote mobility, and training in mapping and orientation within the person's immediate environment;

(2) promote maximum safety in the use of all mobility devices and procedures, including inspection at least quarterly of all equipment used in the mobility program to insure that it is in proper working condition;

(3) actively strive to eliminate architectural barriers, and to modify equipment and facilities to overcome barriers, insuring that multistory buildings are equipped with elevators for the use of mobile nonambulatory persons, and that restrooms, water fountains, and other facilities are accessible for use by mobile nonambulatory persons;

(4) shall make driver education available to those persons who are capable of learning to drive;

(5) promote or help establish generic community transportation services that are usable by disabled persons;

(6) assist persons in securing transportation that enables them to have access to needed programs and services, including transportation after hours and on weekends;

(7) insure that the transportation system is licensed by a State agency; that a current State inspection report is available; that all drivers are trained and licensed; that adequate insurance coverage, including collision, comprehensive, and liability, is in force; that overloads are not permitted; and that transportation provided is adapted to the special needs of the persons receiving such service; and

(8) compile data concerning persons denied or excluded from services because of their unique mobility needs.

Subpart 3—Community Organization

PURPOSE

SEC. 299L. The service delivery system shall be so organized that each person has services available at the time of need, and in close proximity to his or her home. One agency or facility in the service delivery system shall be responsible for implementing a systematic method of collecting data useful for planning and coordinating activities, and shall make available to other facilities and agencies current information on the resources available in the community for serving mentally retarded and other developmentally disabled persons.

RESOURCE INFORMATION AND DATA DOCUMENTATION SERVICES

SEC. 299M. (a) A resource information service shall be established by the agency identified in section 299L to compile and disseminate current and complete listings of all appropriate resources, referral procedures, and other pertinent information. A data documentation service shall be established by the same agency to collect and disseminate data that is useful for planning and coordinating activities.

(b) Within each community a single agency shall provide a centralized resource information and data documentation service.

(c) Each community whose facilities and agencies receive assistance under this Act shall—

(1) maintain a resource information service which shall be an easily identifiable point of contact for professionals and agencies seeking assistance, and which shall:

(A) maintain a current directory of local resources;

(B) have directories of regional and State agencies and facilities serving the local area;

(C) have standing procedures for obtaining, cataloging, and updating information concerning resources and services;

(D) have written policies describing minimum standards for services to which referrals are made;

(E) have regularly followups on its referrals to determine if they were completed, and if they were appropriate to the request for assistance;

(F) analyze referral requests quarterly to determine changing needs and programs, and provide feedback for planning and coordinating purposes;

(G) actively disseminate information about activities, so as to facilitate the resources information and referral activities of other agencies and facilities;

(H) work with other agencies and facilities to improve resource information and referral services;

(I) make materials available for inservice training and community education; and

(J) provide consultation services to support community organization activities;

(2) maintain a data documentation service which shall coordinate its activities with those of other data collection agencies, so as to minimize duplication of effort and encourage the use of standardized reporting systems, and which shall:

(A) collect data at least yearly from all agencies and facilities in the service delivery system;

(B) provide consultation to local agencies in the design of agency reporting systems;

(C) disseminate data for community education and social action programs;

(D) regularly categorize the reasons that persons are rejected for service, and report this information to planning and coordinating bodies as a means of stimulating program modification and development;

(3) work with other agencies in the service delivery system to develop a continuum of services to meet all the needs of the disabled; and

(4) participate in a regular, at least annual, review of the service delivery system that includes, but is not limited to, an analysis of:

(A) the design of system and agency approaches to solving problems;

(B) joint efforts among agencies and facilities to resolve problems in providing services;

(C) the need for integration of ongoing programs within the system;

(D) the identification and resolution of conflicting policies and practices;

(E) the identification and resolution of unnecessary duplication or uneven distribution of services;

(F) the need for simplification and combination of administrative, operational, and funding procedures;

(G) the coordination of data collection and the use of data to study the characteristics and needs of the community; and

(H) the development of standards for personnel selection and performance, and for program evaluation.

COORDINATION

SEC. 299N. (a) Coordination means the process of bringing together all necessary resources in the appropriate sequence in order to accomplish a given objective. Coordination involves initiating, sustaining, and interrelating the various parts of the service delivery system.

(b) Each facility and agency receiving assistance under this Act shall—

(1) have a written statement that clearly defines its role and function within the service delivery system;

(2) have a directory of all other resources and services within the service delivery system;

(3) have cooperative agreements with other components of the service delivery system; and

(4) have established and written procedures for coordination with other components of the service delivery system, including procedures for coordinated planning of services with other agencies, referrals of persons to other agencies, and follow-up referrals.

AGENCY ADVOCACY

SEC. 299O. (a) Agency advocacy means a social action program in which an agency acts to support and safeguard the rights and interests of disabled persons.

(b) Each facility and agency receiving assistance under this Act shall—

(1) participate, where appropriate, with a coalition of other agencies in developing a coordinated plan for agency advocacy, and such a plan shall identify communitywide problems that confront disabled persons and their families, methods for resolving problems within the service delivery system, and strategies for resolving legal or legislative problems that compromise the rights and privileges of disabled persons;

(2) periodically, or as the need arises, make its findings and recommendations known to the public and to appropriate governmental bodies; and

(3) encourage and demonstrate the participation of persons served, their families, and their advocates.

COMMUNITY EDUCATION AND INVOLVEMENT

SEC. 299P. (a) Community education and involvement means an active program of ready, open, and honest communication with the public, aimed at creating community awareness of the needs of mentally retarded and other developmentally disabled persons, and at stimulating social action to meet those needs.

(b) Each facility and agency receiving assistance under this Act shall—

(1) conduct an ongoing community education program that is designed to create community awareness and acceptance of mentally retarded and other developmentally disabled persons, focusing specific attention on understanding the general and special needs of disabled persons, and on the right of disabled persons to participate in the mainstream of community life;

(2) establish a fixed point for collecting and disseminating information and have procedures for disseminating such information during a crisis;

(3) participate in making the community aware of the causes of mental retardation and other developmental disabilities;

(4) educate the general public concerning community programs that are available and needs that remain unmet;

(5) educate the community by employing a variety of techniques such as brochures on services currently provided, fact sheets decribing program components, newsletters, audiovisual materials, a speaker's bureau, program presentations, meetings, and seminars, school

and college class presentations, a total media publicity program, including press releases, staff interviews, and consumer interviews, and a library and bibliography of books and publications for staff, families, and the general public;

(6) identify, and conduct informational sessions for, special audiences, such as public officials;

(7) conduct educational sessions for public and private officials on the advantages of normalized living arrangements for disabled persons, to promote the adoption of zoning ordinances that promote normalization and licensing standards that promote normalization; and

(8) promote community involvement by methods that include, but are not limited to:

(A) using volunteers in the community education program;

(B) involving citizens in writing and contacting their legislators in support of needed legislation;

(C) sponsoring special events that appeal to broad community interests in support of program needs;

(D) conducting activities that express and recognize citizen support of program needs;

(E) recognizing community leaders for their participation in and support of new program developments;

(F) encouraging fraternal, civic, and social organizations to support programs for mentally retarded and other developmentally disabled persons; and

(G) encouraging organizations to invite mentally retarded and other developmentally disabled persons to become members, and to participate in activities with their peers.

PREVENTION

SEC. 299Q. (a) Prevention means the process of arranging forces in the society so as to mitigate or eliminate those factors which contribute to mental retardation or other developmental disabilities.

(b) Each agency or facility receiving assistance under this Act shall—

(1) maintain current information concerning preventive services available in the community, including information necessary to make referrals;

(2) insure that preventive services are readily accessible to any family, regardless of the family's ability to pay for such services;

(3) make provisions for providing or procuring preventive services for all conditions known to entail risk of mental retardation or other developmental disability;

(4) have provisions for ongoing child health pro-

grams, including immunization, screening, regular assessment of physical and mental health, and periodic assessment of development;

(5) insure that highly specialized preventive services, such as genetic screening and counseling, are available, at least on a regional basis; and

(6) insure that services are offered to those who are not aware of their problems, or who are unaccustomed to asking for help;

(7) include current information concerning prevention in orientation and inservice training programs for staff;

(8) participate, where appropriate, with a coalition of other agencies in implementing communitywide preventive activities;

(9) provide opportunities for young people and parents to learn about child development and child rearing, designed to enable participants to understand children by appreciating the various stages of child development, and develop ability and confidence in child rearing;

(10) undertake preventive activities in environmental areas including: amelioration of conditions that adversely affect health, amelioration of social and racial discrimination, reduction of cultural conflicts, and work-

ing to make community resources accessible to those who need them;

(11) undertake biomedical preventive activities including: immunization programs that comply with standards established by the Secretary, voluntary detection or screening programs for infections, voluntary detection or screening programs for endocrine and metabolic disorders, comprehensive health care programs for all women of childbearing age, family planning services, comprehensive prenatal care programs (including nutrition education and services, detection of abnormalities of the placenta and of blood group incompatibilities, and precautions to reduce complications due to radiation, medication, and drug abuse), and comprehensive natal and neonatal care programs to reduce risks due to mechanical, infectious, endocrine, metabolic, neurologic, and nutritional factors, and to toxic drugs; and

(12) undertake special preventive services including genetic screening and counseling and accident prevention and safety programs.

MANPOWER DEVELOPMENT

SEC. 299R. (a) Manpower development means the cooperative process through which the agencies in a community strive to assure the availability of an adequate present and future supply of qualified personnel to work in programs providing services to mentally retarded and other developmentally disabled persons.

(b) Each facility and agency receiving assistance under this Act shall cooperate with other agencies to assure the availability of an adequate present and future supply of qualified personnel through activities such as:

(1) establishing working relationships between agencies and nearby colleges and universities to,

(A) make credit courses, seminars, and workshops available to agency staff, in accordance with their needs, and as related to their occupations,

(B) make agency resources available for training and research, while maintaining the primary goal of serving mentally retarded or other developmentally disabled persons,

(C) permit exchange of staff between agencies and colleges or universities for teaching, research, and consultation,

(D) allow students to visit and observe agency programs, and

(E) allow students to participate in field placements that are supervised by agency staff;

(2) establishing working relationships with other nearby manpower training centers to,

(A) provide follow-up and feedback regarding the effectiveness of training programs,

(B) identify new manpower training needs, and

(C) evaluate manpower training programs yearly; and

(3) participating in training programs conducted by university affiliated facilities, where available.

VOLUNTEER SERVICES

SEC. 2998. (a) Volunteer services means an organized and carefully supervised activity in which the varied skills of unpaid personnel are utilized to support and supplement the efforts of paid agency staff.

(b) Each agency or facility receiving assistance under this Act shall—

(1) use volunteers to support and supplement the activities of its paid staff;

(2) follow established written policies concerning recruitment, selection, training, assignment, supervision, evaluation, recognition, and separation of volunteers;

(3) insure that volunteer participation is open to all persons regardless of sex, race, creed, age, or national origin;

(4) insure that volunteer participation complies with all appropriate State and Federal laws, including those relating to labor and insurance;

(5) insure that volunteer services are available to all persons served, regardless of age, ability, or handicap;

(6) designate a staff member to be responsible for conducting the volunteer services program who shall have education or experience in the administration of volunteer services, devote sufficient time to the administration of the program, in accordance with its size, and have the same relationship to volunteers as a personnel officer has to paid employees;

(7) maintain accurate records concerning volunteer services, including, but not limited to the types, hours, and results of volunteer services provided, individuals and organizations providing services; materials and money received, and operational expenditures; and

(8) provide a volunteer services advisory committee, composed of representatives from the agency, the consumer population and the community, plans, reviews, and recommends improvements in the volunteer program.

Subpart 4—Program Evaluation

PROGRAM EVALUATION

SEC. 229T. (a) Program evaluation means a process in which program outcomes are measured against the previously stated goals and objectives of the agency.

(b) Each agency or facility receiving assistance under this Act shall—

(1) have a written statement of its goals and objectives, insuring that such objectives are related to the objectives of the service delivery system of which the agency is a part, and to the identified needs of the population served by such service delivery system, and that such objectives define the population to be served, the services to be provided, and the modalities to be utilized in providing these services;

(2) periodically, and at least annually, evaluate its performance against its stated goals and objectives, including in such evaluation assessment of the agency's objectives, the relation of the agency's objectives to the objectives specified in the individual program plans, agency program standards, program methodologies, staff performance, staffing requirements;

(3) provide for staff, persons served and family involved in the evaluation process;

(4) measure the effectiveness of its programs and services in terms of the progress of persons served toward the objectives specified in their individual program plans;

(5) have procedures for continuous monitoring of the person's progress toward the objectives stated in his individual program plan;

(6) provide in its evaluation process mechanisms for the consequent review and modification of objectives, policies, and practices;

(7) insure where cooperative efforts among agencies are designed to achieve a common goal, provide that services are evaluated cooperatively and in relation to one another;

(8) have evidence of its cooperative efforts with other agencies to develop a continuum of services to meet all of the needs of mentally retarded and other developmentally disabled persons; and

(9) insure that the number of persons served by agencies in the service delivery system is consistent with the needs for service, as determined by a survey of community needs;

(10) insure that appropriate alternatives and options exist within the system to meet the varied needs of mentally retarded and other developmentally disabled persons; and

(11) provide its funding sources with qualitative evidence of accomplishments and shortcomings in relation to its stated goals and objectives, documenting its efforts to facilitate maximum coordination among its funding sources with respect to licensing requirements, required

reports, accountability requirements, and delays between approval and receipts of funds.

Subpart 5—Research and Research Utilization

RESEARCH AND UTILIZATION

SEC. 229V. (a) Research means a systematic and detailed attempt to discover or confirm facts relating to the problems associated with mental retardation and other developmental disabilities. Research utilization shall include the dissemination of research findings and the use of such findings to improve services to and for mentally retarded and other developmentally disabled persons.

(b) Each agency and facility receiving assistance under this Act shall—

(1) indicate in its statement of purposes whether or not the agency will engage in research activities;

(2) provide a written policy concerning the purpose and conduct of all research involving the agency's staff, persons served, or services;

(3) consult agency staff members regarding the development of research efforts in their areas of competence and interest, and make available to staff members who have identified researchable problems, and who are equipped by interest and training to conduct applied or basic research opportunities, resources, and other

necessary research assistance and insure that an agency staff member is assigned to provide liaison with each research project conducted by outside investigators.

(4) establish an interdisciplinary research committee that includes both agency staff members and qualified persons who are not members of the agency's staff who shall be qualified by training and experience to conduct initial and continuing reviews of research projects; and such committee shall review all proposed studies to insure adequacy of research design, implementation of ethical standards in the design, and compliance with the regulations published by the Department of Health, Education, and Welfare, maintaining a continuing review of all research activity;

(5) establish a human rights committee to assure that the rights and welfare of research subjects are protected, and such committee shall include disabled persons or their representatives, and relevantly qualified professionals who are not involved in the research project under review; and the committee shall insure that informed consent is obtained by adequate and appropriate methods, that methods for obtaining informed consent are reviewed at least annually, and that disabled persons are not used as a captive source of research subjects for purposes unrelated to their specific welfare, unless

they or their families have agreed to the research, and the research is in no way detrimental to their welfare;

(6) provide procedures for obtaining informed consent that include:

(A) a fair explanation of the procedures to be followed, including an identification of those that are experimental;

(B) a description of the attendant discomforts and risks;

(C) a description of the benefits to be expected;

(D) a disclosure of appropriate alternative procedures that would be advantageous for the subject;

(E) an offer to answer any inquiries concerning the procedures; and

(F) an instruction that the subject is free to withdraw his or her consent and ,to discontinue participation in the project or activity at any time;

(7) insure that the written or oral agreement entered into by the subject includes no exculpatory language through which the subject is made to waive, or appear to waive, any of his or her legal rights, or to release the agency or its agents from liability for negligence;

(8) insure that the individual conducting research involving human subjects is affiliated with or sponsored by an agency that can and does share responsibility for the protection of the subjects involved;

(9) provide appropriate guidelines to deal with any emergency that may develop, even in the course of seemingly routine research activities;

(10) insure that investigators and others directly involved in research adhere to the ethical standards of their professions concerning the conduct of research and obtain informed consent from each subject, or have access to the record of informed consent;

(11) insure that the principal investigator of each completed research project is responsible for communicating to the staff of the agency the purpose, nature, outcome, and possible practical or theoretical implications of the research and that outside researchers have the same obligations relative to staff information and feedback as do agency staff members;

(12) insure that copies of reports resulting from research projects shall be maintained in the agency and that the agency assists in disseminating the results of its research to other units of the service delivery system, assuring that when research findings are made

public, the anonymity of individual persons and parents is maintained;

(13) have a mechanism to review research findings external to the agency, and to implement those findings that will improve the quality of services being provided; and

(14) cooperate with programs of research and research training that are conducted by colleges, universities, and research agencies, or by other qualified investigators.

Subpart 6—Records

RECORDS

SEC. 299W. (a) The person's record is a compilation of data that provides the basis for planning and evaluating his or her individual program plan; that provides a means of communication among all staff members who are involved in implementing that plan; that furnishes evidence of the person's progress; that serves as a basis for review and evaluation of the agency's programs; that assists in protecting the legal rights of the person, the staff, and the agency; and that provides data for use in research and education.

(b) The establishment and maintenance of a functional records system shall be an essential activity of each community service program. Records shall document the services provided the person, and any action taken in his or her behalf, contacts with persons who were rejected for service, or who were referred to other agencies, shall be available to parents and persons served upon demand, and shall record only objective data and observable behaviors.

(c) Each facility and agency receiving assistance under this Act shall—

(1) insure that a record is maintained for each person that is adequate for:

(A) developing and continuously evaluating the individual program plan;

(B) providing a means of communication among all persons contributing to the individual program plan;

(C) recording progress in achieving the objectives specified in the individual program plan;

(D) serving as a basis for review, study, and evaluation of the programs provided by the agency for its patients;

(E) protecting the legal rights of the person, agency, and staff; and

(F) providing data for use in research and education;

(2) insure that all information pertinent to the above stated purposes is incorporated in the person's

record in sufficient detail and clarity to enable those persons involved in implementing the individual program to provide effective, continuing services, and insure that all entries in the record are legible, dated, authenticated by the signature and identification of the person making the entry, to the extent possible, written in non-technical terms, and include symbols and abbreviations only if they are in a list approved by the agency's chief executive officer, and if a legend understood by the staff is provided to explain them;

(3) assist the family in establishing and maintaining a record to document its role in implementing the individual program plan;

(4) insure that the person's record shall be available to the family and that person upon demand;

(5) insure that the following information shall be obtained and entered in the person's record at the time of entry to the program:

(A) name, date of initial conduct, date of birth, citizenship status, marital status, and social security number;

(B) sex, race, height, weight, color of hair, color of eyes, identifying marks, and recent photograph;

(C) name and address of parents, legal guardian, advocate, or next of kin;

(D) reason for entry, referral, or rejection;

(E) legal competency status;

(F) language spoken or understood;

(G) sources of support, including social security, veterans' benefits, and insurance;

(H) information relevant to religious affiliation;

(I) reports of previous histories, evaluations, or observations;

(J) age at onset of disability;

(K) name and address of family physician or health facility providing medical care; and

(L) medication history;

(6) insure that within the period of three months after initial contact, there shall be entered in the person's record:

(A) a report of the review and updating of the entry information;

(B) a statement of short-term goals that can be used for programing and placement;

(C) a comprehensive assessment and individual program plan, designed by an interdisciplinary team; and

(D) when possible, a diagnosis based on the

American Association on Mental Deficiency (AAMD) Manual on Terminology and Classification in Mental Retardation; the Diagnostic and Statistical Manual of Mental Disorders, second edition (DSM-II), published by the American Psychiatric Association; or another accepted standard nomenclature;

(7) insure that record entries during the period of service shall include:

(A) reports of regular and specific reviews and evaluations of the individual program plan;

(B) observations of response to the individual program plan, recorded with sufficient frequency to enable evaluation of its efficiency;

(C) records of significant behavior incidents;

(D) records of agency contacts with the person's family or guardian;

(E) records of services provided, and attendance;

(F) periodic updating of the information recorded at the time of initial contact;

(G) appropriate authorizations and consents; and

(H) medication response profile;

(8) insure that a discharge summary shall be entered in the record within seven days after the time of termination of agency services, which shall include—

(A) a brief recapitulation of findings, events, and progress during the period of service;

(B) specific recommendations and arrangements for future programing and follow along services; and

(C) the agency's evaluation of the appropriateness of the reason for terminating agency services, when termination is contrary to the agency's recommendation;

(9) insure that all information contained in the person's record, including information contained in an automated data bank, shall be privileged and confidential, including assurances that—

(A) the agency shall be responsible for safekeeping of any record, and for securing it against loss or use by unauthorized persons;

(B) the record may be removed from the agency's jurisdiction and safekeeping only in accordance with court order, subpena, or statute;

(C) there shall be written policies governing access to, duplication of, and dissemination of information in the record;

(D) information in the record may be released only after the requesting individual or agency clearly documents the need to know; and

(E) written account of the person or his or her family shall be required for the release of information to persons not otherwise authorized to receive it;

(10) maintain an organized record system for the collection and dissemination of information regarding persons served, which is compatible with an existing community or State system; contains all information pertaining to the person; where particular professional services require the maintenance of separate records, includes a summary of the information entered in the person's unit record; are readily accessible to authorized personnel; are periodically reviewed to assure that they are current and complete, and that they meet agency, community, or State standards; include a master index of all persons seen by the agency; and are retained for a reasonable period of time as specified by the agency;

(11) insure that statistical information includes at least the following:

(A) number of persons served by age group, sex, race, and place of residence;

(B) number of persons served by level of retardation, according to regulations prescribed by the Secretary;

(C) number of persons served by level of adaptive behavior, according to regulations prescribed by the Secretary;

(D) number of persons with physical disabilities;

(E) number of persons served who are ambulatory, mobile nonambulatory, and nonmobile;

(F) number of persons with sensory defects;

(G) number of persons with communication handicaps;

(H) number of persons with convulsive disorders;

(I) number of persons with emotional and behavioral problems;

(J) number of persons served by etiological diagnosis, according to regulations prescribed by the Secretary;

(K) number of persons with multiple disabilities, inclusive of numbers listed separately in preceding categories;

(L) movement of persons into, out of, and, within the agency; and

(M) length of service; and

(12) insure that data is reported to appropriate community, State, and Federal agencies as required.

Subpart 7—Administration

PHILOSOPHY, POLICIES, AND PRACTICES

Sec. 299X. (a) Administration means that segment of an agency that determines its mission and purpose, and that is responsible for planning, organizing, directing, controlling, and coordinating the activities of the organization.

(b) Each agency or facility receiving assistance under this Act shall—

(1) have a written statement of philosophy that stipulates its mission, purpose, and role in the service delivery system:

(A) Copies of this statement shall be distributed to agency staff and shall be available to persons served, consumer representatives, and the interested public;

(2) insure that the ultimate aim of the agency is to foster those behaviors that maximize the human qualities of the disabled person, increase the complexity of behavior, and enhance ability to cope with the environment:

(A) the agency shall accept and implement the principle of normalization, defined as the use of means that are as culturally normative as possible to elic[illegible]nd maintain behavior that is as culturally normative as possible, taking into account local and subcultural differences; and

(B) the agency's philosophy and goals shall require the use of the least restrictive alternatives that are consistent with the developmental needs and objectives of its clients;

(3) facilitate integration by seeking to make generic services accessible to the consumer population when appropriate to its needs;

(4) insure that the agency and its service delivery unit shall be located within, and shall be conveniently accessible to, the population served;

(5) regulate its services and resources to those of all other agencies in its community;

(6) have a written statement of policies and procedures concerning the rights of the consumer population that:

(A) assures the civil rights of all persons; and

(B) defines the means of making legal counsel available to persons, for the protection of their rights;

(7) have a written statement of policies and procedures that protect the financial interests of its consumer population and that provide for:

(A) determining the financial benefits for which consumer population are eligible; and

(B) assuring that consumer population receive the funds for incidentals and for special needs (such as specialized equipment) that are due them under public and private support programs;

(8) have evidence that the views and opinions of the person on matters concerning him or her are elicited and given consideration in defining the processes and structures that affect the person, unless the person is clearly unable to communicate in any way:

(A) The agency shall have written procedures for the appeal of agency decisions by a person or his or her family; and

(B) The agency shall have written procedures for notifying a person's family in the event of an emergency;

(9) have a waiting list policy and procedure that specifies the interim services to be provided persons who have not been admitted to programs. The agency shall provide assisted referral services to any person upon request.

(10) require that services provided its consumer population by other agencies meet the standards for quality of services as stated in this title, and all contracts

for the provision of such services stipulate that these standards shall be met.

(11) insure that residential services provided by the agency comply with the standards of title II of this Act.

(12) have documentary evidence of its source of operating authority:

(A) A public agency shall have documents that describe the administrative framework of the governmental department in which it operates;

(B) A private agency shall have documents that include its charter, its constitution and bylaws, and, where required, its state license.

(13) insure that the governing body of the agency shall exercise general direction and shall establish policies concerning the operation of the agency and the welfare of the clients served:

(A) if the governing body is a board:

(i) its members shall visit all program components of the agency during operating hours; and

(ii) the agency shall provide orientation and training for new members.

(14) insure that the governing body shall establish a job description for the position of chief executive officer,

including appropriate qualifications of education, experience, personal factors and skills.

(15) insure that the governing body employs a chief executive officer so qualified, and delegates to him or her authority and responsibility for the management of the affairs of the agency in accordance with established written policy. Procedures shall provide for the designation of an individual to be in charge of the agency when the chief executive officer is not available.

(16) provide for meaningful and extensive consumer and public participation in the development of agency policies, through the following means:

(A) If the agency has a governing board, its members include consumers or their representatives, interested citizens, and relevantly qualified professionals presumed to be free of conflicts of interest;

(B) If the agency does not have a governing board, its governing body actively seeks advice from an advisory board composed as described above; and

(C) The agency shall provide for periodic peer review, or consumer advisory committee assessment, of agency practices and services, including services provided by other agencies that support those provided by the agency itself.

(17) be administered and operated in accordance with sound management principles. The type of administrative organization of the agency shall be appropriate to the program needs of its consumers. The agency shall have a current table of organization that shows the governance and administrative pattern of the agency. The organization shall provide effective channels of communication in all directions.

(18) have a policies and procedures manual that describes the current methods, forms, processes, and sequences of events that are utilized to achieve its objectives and goals. These policies and procedures shall be:

(A) consistent with the needs of the agency's consumers;

(B) consistent with the agency's philosophy and objectives;

(C) consistent with currently accepted theories, principles, and goals;

(D) consistent with the resources available; and

(E) applicable to all services provided.

(19) have copies of the laws, rules, and regulations that are relevant to its functions.

(20) have implemented a plan for a continuing management audit to insure that:

(A) effective implementation of its stated policies and procedures; and

(B) compliance of its policies and procedures with laws and regulations.

(21) have a written plan for improving the quality of staff and services that reflects the staff's programmatic responsibilities in establishing and maintaining standards for services to clients:

(A) Each program component of the agency shall be licensed by the appropriate State agency; and

(B) The services of consultants not directly associated with the agency shall be available to the staff of each program.

(22) provide for effective staff and consumer participation and communication in the following ways:

(A) Staff meetings shall be held regularly;

(B) Standing committees appropriate to the agency shall meet regularly;

(C) Committees shall include client participation whenever appropriate;

(D) Minutes and reports of staff meetings and of standing and ad hoc committee meetings, including records of recommendations and their implementation, shall be kept and filed;

(E) Summaries of the minutes and reports of staff and committee meetings shall be distributed to participants and to appropriate staff members; and

(F) Summaries of the minutes and reports of governing board meetings shall be distributed to staff and to consumer representatives.

(23) have a sufficient number of appropriately qualified and adequately trained personnel to conduct

(24) provide space, equipment, and an environ-

in this title.

(24) provide space, equipment, and an environment that is appropriate and adequate for conducting its program in accordance with the standards specified in this title.

(25) insure that funds are budgeted and spent in accordance with the principles and procedures of program budgeting:

(A) The fixed and incremental costs for adequate programing for the person shall be recorded;

(B) The budget requests submitted by the agency shall reflect its program needs, as developed by its staff;

(C) The budget requests submitted by the agency shall be documented and interpreted;

(D) Budget performance reports shall be prepared at appropriate intervals and shall be submitted to those staff and governing board members who participate in budget and management responsibilities; and

(E) There are provisions for rebudgeting of funds in accordance with changing program needs;

(26) insure that individuals acting on the agency's budget requests (such as board members, State budget officials, and members of appropriations committees) shall have firsthand knowledge of its operation and needs, obtained by regular visitation and observation of its programs;

(27) insure that a full audit of the agency's fiscal activities is performed annually by a qualified accountant independent of the agency;

(28) insure that fiscal reports are prepared annually and communicated to the agency's public;

(29) insure that there are written purchasing policies regarding authority and approvals for supplies, services, and equipment;

(30) have insurance that includes, but not limited to, insurance against public and professional liability, fire, theft, and disaster;

(31) provide that charges for services shall have a written schedule of rates and charge policies that is available to all concerned;

(32) insure that fundraising activities comply with local and State laws and with applicable ethical practices;

(63) insure that adequate services for personnel administration shall be provided by means appropriate to the size and function of the agency;

(34) provide a statement of its personnel policies and practices which insures:

(A) the hiring, assignment, and promotion of employees shall be based on their qualifications and abilities without regard to sex, color, creed, age, irrelevant disability, marital status, ethnic or national origin, or membership in an organization;

(B) there shall be written job descriptions for all positions;

(C) personnel shall be licensed, certified, or registered as required by the State in which the agency is located;

(D) paraprofessional personnel shall be supervised by qualified and licensed, certified, or registered supervisory personnel;

(E) each professional staff member shall be familiar with and shall adhere to the code of ethics and standards of practice promulgated by his or her professional organization;

(F) all personnel shall be medically determined to be free of communicable and infectious diseases at the time of employment and annually thereafter. All personnel shall undergo a medical examination at the time of employment and annually thereafter;

(G) all employees shall be appointed for a limited probationary period in order to determine if they are capable of fulfilling the specific requirements of their jobs;

(H) each employee shall be evaluated at least annually after the initial trial period. The evaluation shall be:

(i) reviewed with the employee; and

(ii) recorded in the employee's personnel record;

(I) there shall be an authorized procedure, consistent with due process, for suspension or dismissal of an employee for cause;

(J) methods of improving the welfare and security of employees shall include:

(i) a merit system or its equivalent;

(ii) a salary schedule covering all positions;

(iii) effective grievance procedures;

(iv) provisions for vacations, holidays, and sick leave;

(v) provisions for health insurance and retirement;

(vi) permitting employee organizations;

(vii) opportunities for continuing educational experiences, including educational leave; and

(viii) provisions for recognizing outstanding contributions to the agency;

(K) a statement of the agency's personnel policies and practices shall be provided to all its employees;

(35) develop with each consultant, professional, and paraprofessional staff member a performance description of his or her assigned duties. Each performance description shall include, but not be limited to:

(A) the staff member's accountability for accomplishing mutually determined objectives;

(B) the staff member's role in implementing individual program plans;

(C) the development of outcome measures to evaluate the staff member's performance;

(D) specified performance evaluation techniques; and

(E) a signed performance description agreement between the agency and the staff member;

(36) provide a written statement of the agency's policies and procedures for handling cases of neglect or abuse of its clients. Alleged violations shall be reported immediately:

(A) all alleged violations shall be thoroughly investigated, using specified investigation procedures;

(B) at least preliminary results of such investigations shall be reported to the chief executive officer, or his or her designated representative, within twenty-four hours of the report of the incident;

(C) the results of the investigation shall be recorded in the employee's personnel record; and

(D) sanctions shall be invoked when an allegation is sustained;

(37) staff shall be sufficient so that the agency is not dependent upon the use of the consumer population or volunteers for productive services. There shall be a written policy for protecting persons from exploitation when

they are engaged in training and productive work. Persons who function at the level of staff in occupational or training activities shall have the same privileges as staff, and be paid at the same legally required wage level when employed in other than training situations;

(38) insure that a staff development program is provided that includes:

(A) orientation for all new employees to acquaint them with the philosophy, organization, program, practices, and goals of the agency;

(B) induction training for each new employee, so that his or her skills in working with the consumer population are increased;

(C) inservice training for employees who have not achieved the desired level of competence, and opportunities for continuous inservice training to update and improve the skills and competencies of all employees;

(D) supervisory and management training for all employees in, or candidates for, supervisory positions;

(E) training programs designed to facilitate an increase in personal effectiveness, as well as lateral and upward movement;

(F) emphasis on interdisciplinary training programs;

(G) studies to assess the training needs of the staff; and

(H) participation of appropriate staff in staff development programs; and

(39) insure that provision is made for all staff members to improve their competencies by:

(A) attending staff meetings;

(B) attending seminars, conferences, workshops, and institutes;

(C) attending college and university courses;

(D) visiting other agencies and facilities;

(E) participating in professional organizations;

(F) conducting research;

(G) publishing studies; and

(H) having access to a professional library.

(40) If the agency provides food services, provide a written statement of goods, policies, and procedures that:

(A) shall govern all food services and nutrition activities;

(B) shall be in compliance with State and local regulations;

(C) shall provide for a planned, nutritionally adequate diet;

(D) shall contain provisions for feeding persons who have special needs, and for the development of self-feeding skills, including attention to such matters as the texture of food and needs for special diets, feeding techniques, and equipment;

(E) shall be prepared by, or with the assistance of, a nutritionist or dietitian;

(F) shall be reviewed regularly by the nutritionist or dietition; and

(G) shall be distributed to agency personnel;

(41) Persons with special eating disabilities are provided with an interdisciplinary approach to the diagnosis and remediation of their problems, consistent with their developmental needs;

(42) Provide when food services are not directed by a nutritionist or dietitian, that regular consultation with a nutritionist or dietitian shall be documented; and

(43) Provide that copies of the daily menu shall be posted; and kept on file for at least thirty days;

(44) Insure that the requirements of the Secretary, with regard to fire safety, shall be met, with specific reference to the following:

(A) provision of adequate and alternate exits and exit doors;

(B) provision of exit markings at each exit;

(C) provision of exit ramps, with nonskid surface and slope not exceeding one foot in twelve; and

(D) provision of handrails on stairways;

(E) there shall be records that document compliance with the regulations of the State or local fire safety authority that has primary jurisdiction over the agency;

(F) aisles and exits shall be free from all encumbrances, and floors shall be uncluttered:

(G) Flammable materials shall be properly stored and safeguarded; and

(H) There shall be records of periodic fire safety inspections and reports;

(45) insure that records that document compliance with the sanitation, health, and environmental safety codes of the State or local authority having primary jurisdiction over the agency:

(A) Written reports of inspections by State or local health authorities shall be kept on file; and

(B) Handwashing facilities shall be available in, or immediately adjacent to, all restrooms, kitchens, and treatment rooms;

(46) have evidence that it is aware of the provisions of the Occupational Safety and Health Act of 1970;

(47) insure that insurance company written inspection reports and records are kept on file;

(48) have a written staff organization plan and written procedures, that are communicated to the staff and reviewed by the staff annually, for meeting all potential emergencies and disasters, such as fire, severe weather, and missing persons:

(A) the plan and procedures shall be posted at suitable locations throughout the agency;

(49) insure that evacuation drills are held at least quarterly for each shift of agency personnel, and under varied conditions and the results of each drill shall be recorded;

(50) insure that all buildings and outdoor recreation facilities constructed after December 31, 1974, are accessible to, and usable by, the nonambulatory, and shall meet all applicable specifications for making buildings accessible to, and usable by, the physically handicapped;

(A) All existing buildings and outdoor recreation facilities shall be modified so as to conform to the above requirements not later than December 31, 1979, and

(B) Existing facilities shall provide,

(i) Entrance ramps wide enough for wheelchairs, not exceeding a rise of one foot in twelve, with nonslip surfaces, and with rails on both sides,

(ii) Doorways and corridors wide enough for wheelchairs, and

(iii) Grab bars in toilet and bathing facilities; and

(51) use paint that is lead free and insure that old paint and plaster containing lead shall be removed or covered in such a manner that it is not accessible to any person.

94TH CONGRESS
1ST SESSION

S. 1194

IN THE SENATE OF THE UNITED STATES

MARCH 17 (legislative day, MARCH 12), 1975

MR. STAFFORD (by request) introduced the following bill; which was read twice and referred to the Committee on Labor and Public Welfare

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A BILL

To revise and extend the program authorized by the Developmental Disabilities Services and Construction Act.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That this Act may be cited as the "Developmentally Disabled Assistance Act of 1975".

TITLE I—GENERAL PROVISIONS

DECLARATION OF PURPOSE AND FEDERAL SHARE

SEC. 101. (a) The purpose of this Act is to improve and coordinate the provision of services to persons with developmental disabilities through (A) grants to assist the several States in developing and implementing a comprehensive and continuing plan for meeting the current and future needs of persons with developmental disabilities; (B) support of interdisciplinary training programs and training demonstration projects at institutions of higher education; and (C) the support of other activities which will contribute to improving the condition of persons with developmental disabilities.

(b) The Federal share with respect to any project assisted under title II of this Act may not exceed 70 per centum of the necessary cost thereof as determined by the Secretary.

(c) The Federal share with respect to assistance under title III of this Act may not exceed 70 per centum of the necessary cost thereof, as determined by the Secretary, for the fiscal year ending June 30, 1975, 60 per centum of such cost for the fiscal year ending June 30, 1976, and 50 per centum of such cost for the fiscal year ending September 30, 1977.

(d) (1) The non-Federal share of the cost of any project assisted under this Act shall be provided in cash or in kind, in accordance with rules generally applicable to grants provided by the Department of Health, Education, and Welfare.

(2) Payments of grants under this Act shall be made in advance or by way of reimbursement, and on such conditions as the Secretary may determine.

(3) For the purpose of determining the Federal share

with respect to any State, expenditures by a political subdivision thereof or by nonprofit private agencies, organizations, and groups shall, subject to such limitations and conditions the Secretary may by regulation prescribe, be deemed to be expenditures by such State.

DEFINITIONS

SEC. 101. For purposes of this Act—

(1) "construction" means the construction of new buildings, the acquisition, expansion, remodeling, alteration, and renovation of existing buildings, and initial equipment of any such buildings (including medical transportation facilities);

(2) "cost of construction" means the amount necessary for the construction of a project, including architect's fees and the cost of the acquisition of land, but excluding the cost of offsite improvements;

(3) "design for implementation" means a document prepared by the appropriate State agency or agencies outlining the implementation of the State plan as developed by the State planning council. The design for implementation shall include details on the methodology of implementation priorities for spending, a detailed plan for the use of funds provided under this Act, specific objectives to be achieved, a listing of those programs and resources to be utilized, and a method for periodic evalu-

ation of its effectiveness in meeting State plan objectives;

(4) "developmental disability" means a disability attributable to mental retardation, cerebral palsy, epilepsy, autism, or another neurological condition of an individual found by the Secretary to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals, which disability originates before such individual attains age eighteen, which has continued or can be expected to continue indefinitely, and which constitutes a substantial handicap to such individual;

(5) "institution of higher education" has the meaning given it in section 122(c) of the Education Amendments of 1972;

(6) "nonprofit facility for persons with developmental disabilities", or "nonprofit private institution of higher learning" means a facility for persons with developmental disabilities, and an institution of higher learning which is owned and operated by one or more nonprofit corporations or associations no part of the net earnings of which inures, or may lawfully inure, to the benefit of any private shareholder or individual;

(7) "nonprofit private agency or organization" means an agency or organization which is a nonprofit corporation or association or which is owned and operated by one or more of such corporations or associations;

(8) "Secretary" means the Secretary of Health, Education, and Welfare;

(9) "services for persons with developmental disabilities" means specialized services or special adaptations of generic services directed toward the alleviation of a developmental disability or toward the social, personal, physical, or economic habilitation or rehabilitation of an individual with such a disability, and such term includes diagnosis, evaluation, treatment, personal care, day care, domiciliary care, special living arrangements, training, education, sheltered employment, recreation, counseling of the individual with such disability and of his family, protective and other social and legal services, information and referral services, follow-along services, and transportation services necessary to assure delivery of services to persons with developmental disabilities;

(10) "State" includes the several States, Puerto Rico, Guam, American Samoa, the Virgin Islands, the

Trust Territory of the Pacific Islands, and the District of Columbia; and

(11) "title" when used with reference to a site for a project, means a fee simple, or such other estate or interest (including a leasehold on which the annual rental does not exceed 4 per centum of the value of the land) as the Secretary finds sufficient to assure for a period of not less than fifty years undisturbed use and possession for the purposes of construction and operation of the project.

AUDIT

SEC. 102. Each recipient of a grant or contract under this Act shall keep such records as the Secretary may prescribe, including records which fully disclose the amount and disposition by such recipient of the proceeds of such grant or contract, the total cost of the project or undertaking in connection with which such grant or contract is made or funds thereunder used, the amount of that portion of the cost of the project or undertaking supplied by other sources, and such records as will facilitate an effective audit. The Secretary and the Comptroller General of the United States, or any of their duly authorized representatives, shall have access for the purpose of audit and examination to any books, documents, papers, and records of the recipient of any grant or contract under this Act which are pertinent to such grant or contract.

TITLE II—DEMONSTRATION AND TRAINING GRANTS FOR UNIVERSITY-AFFILIATED FACILITIES

DEMONSTRATION AND TRAINING GRANTS

SEC. 201. (a) For the purposes of assisting institutions of higher education to contribute more effectively to the solution of complex health, education, and social problems of children and adults suffering from developmental disabilities, the Secretary may, in accordance with the provisions of this title, make grants to cover costs of administering interdisciplinary training programs and other demonstration training programs for personnel who are serving, or preparing to serve, persons with developmental disabilities. Such programs may be directed toward established disciplines as well as new kinds of training to meet critical shortages in the care of persons with developmental disabilities.

(b) For the purpose of making grants pursuant to this section, there are authorized to be appropriated for the fiscal year ending June 30, 1975, and for each of the two succeeding fiscal years, $4,250,000.

APPLICATIONS

SEC. 202. Applications for grants under this title may be approved by the Secretary, only if the applicant is a college or university operating a program of the type described in section 201 (a), or is a public or nonprofit private agency or organization operating such a facility. In considering applications for such grants, the Secretary shall give priority to any application which shows that the applicant has made arrangements, in accordance with regulations of the Secretary, for a junior college or other community-based educational or health facility to participate in the programs for which the application is made.

MAINTENANCE OF EFFORT

SEC. 203. Applications for grants under this title may be approved by the Secretary only if the application contains or is supported by reasonable assurances that the grants will not result in any decrease in the level of State, local, and other non-Federal funds for services for persons with developmental disabilities and training of persons to provide such services which would (except for such grant) be available to the applicant, but that such grants will be used to supplement, and, to the extent practicable, to increase the level of such funds.

TITLE III—GRANTS FOR PLANNING, PROVISION OF SERVICES, AND CONSTRUCTION AND OPERATION OF FACILITIES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

AUTHORIZATION OF APPROPRIATION

SEC. 301. For the purpose of making grants to carry out this title, there are authorized to be appropriated $30,875,000 for the fiscal year ending June 30, 1975, and for each of the two succeeding fiscal years.

STATE ALLOTMENTS

SEC. 302. (a) (1) From the sums appropriated pursuant to section 301 for each fiscal year, the several States shall be entitled to allotments determined, in accordance with regulations, on the basis of (A) the population, (B) the extent of need for services and facilities for persons with developmental disabilities, and (C) the financial need of the respective States; except that the allotment of any State (other than the Virgin Islands, American Samoa, Guam, and the Trust Territory of the Pacific Islands) for any such fiscal year shall be not less than $200,000 and the allotment of the Virgin Islands, American Samoa, Guam, and the Trust Territory of the Pacific Islands shall be not less than $50,000.

(2) In determining, for purposes of paragraph (1), the extend of need in any State for services and facilities for persons with developmental disabilities, the Secretary shall take into account the scope and extent of the services specified, pursuant to section 304(b), in the State plan of such State approved under this title.

(3) Sums allotted to a State for a fiscal year and designated by it for construction, renovation, or modernization which are unobligated at the end of such year shall remain available to such State for such purpose for the next fiscal

year and for such year only, in addition to the sums allotted to such State for such fiscal year.

(b) Whenever a State plan is approved in accordance with section 304 which provides for participation of more than one State agency in administering or supervising the administration of designated portions of such plan, the State may apportion its allotment among such agencies in a manner which is reasonably related to the responsibilities assigned to such agencies in carrying out the purposes of this title, subject to the approval of the Secretary. Funds so apportioned to State agencies may be combined with other State or Federal funds authorized to be expended for other purposes, provided the purposes of this title will receive proportionate benefit from the combination.

(c) Whenever a State plan approved in accordance with section 304 (c) provides for cooperative or joint effort between States or between or among agencies, public or private, in more than one State, portions of funds allotted to one or more such cooperating States or agencies may be combined in accordance with the agreements between the agencies and States involved.

(d) The amount of an allotment to a State for a fiscal year which the Secretary determines will not be required by the State during the period for which it is available for the purpose for which it is allotted shall be available for reallotment by the Secretary on such date or dates as he may fix (but not earlier than thirty days after he has published notice of his intention to make such reallotment in the Federal Register), to other States with respect to which such a determination has not been made, in proportion to the original allotments of such States for such fiscal year, but with such proportionate amount for any of such other States being reduced to the extent it exceeds the sum the Secretary estimates such State needs and will be able to use during such period; and the total of such reductions shall be similarly reallotted among the States whose proportionate amounts were not so reduced. Any amount so reallotted to a State for a fiscal year shall be deemed to be a part of its allotment under subsection (a) for such fiscal year.

(e) The Secretary shall administer grants under this title in accordance with policies used generally to administer grants throughout the Department of Health, Education, and Welfare.

NATIONAL COUNCIL ON SERVICES AND FACILITIES FOR THE DEVELOPMENTALLY DISABLED

SEC. 303. (a) (1) The National Advisory Council on Services and Facilities for the Developmentally Disabled (hereinafter referred to as the "Council"), which was established pursuant to section 133 of the Developmental Disabilities Services and Facilities Construction Act, shall continue to exist for the period for which appropriations are authorized under this Act. The Council shall consist of twenty members, not otherwise in the regular full-time employ of the United States, to be appointed by the Secretary without regard to the provisions of title 5, United States Code, governing appointments in the competitive civil service.

(2) The Secretary shall from time to time designate one of the members of the Council to serve as Chairman thereof.

(3) The members of the Council shall be selected from leaders in the fields of service to the mentally retarded and other persons with developmental disabilities, including leaders in State or local government, in institutions of higher education, and in organizations representing consumers of such services. At least five members shall be representative of State or local public or nonprofit private agencies responsible for services to persons with developmental disabilities, and at least five shall be representative of the interests of consumers of such services.

(b) Each member of the Council shall hold office for a term of four years, except that any member appointed to fill a vacancy occurring prior to the expiration of the term for which his predecessor was appointed shall be appointed for the remainder of such term.

(c) It shall be the duty and function of the Council to (1) advise the Secretary with respect to any regulations promulgated or proposed to be promulgated by him in the implementation of this title, and (2) study and evaluate programs authorized by this Act with a view of determining their effectiveness in carrying out the purposes for which they were established.

(d) The Council is authorized to engage such technical assistance as may be required to carry out its functions, and the Secretary shall, in addition, make available to the Council such secretarial, clerical, and other assistance and such statistical and other pertinent data prepared by or available to the Department of Health, Education, and Welfare as it may require to carry out such functions.

(e) Members of the Council, while attending meetings or conferences thereof or otherwise serving on the businesss of the Council, shall be entitled to receive compensation at rates fixed by the Secretary, but at rates not exceeding the daily equivalent of the rate provided for GS-18 of the General Schedule for each day of such service (including travel time), and, while so serving away from their homes or regular places of business, they may be allowed travel expenses, including per diem in lieu of subsistence, as authorized by section 5703 of title 5, United States Code, for persons in the Government service employed intermittently.

STATE PLANS

SEC. 304. (a) For each fiscal year in which a State makes application to participate in programs under this title it shall develop, submit, and obtain the approval of the Secretary of an annual State plan which is a specific goal oriented plan, which shall include provisions designed to—

(1) reduce and eventually eliminate inappropriate institutional placement of persons with developmental disabilities;

(2) improve the quality of care, habilitation, and rehabilitation of persons with developmental disabilities for whom institutional care is appropriate;

(3) provide early screening, diagnosis, and evaluation of developmentally disabled infants and preschool children (including maternal care, developmental screening, home care, infant and preschool stimulation programs, and parent counseling and training);

(4) provide counseling, program coordination, follow-along services, and protective services on behalf of developmentally disabled adults;

(5) support the establishment of community programs as alternatives to institutionalization, designed

to provide services for the care and habilitation of persons with developmental disabilities, which programs utilize, to the maximum extent feasible, the resources and personnel in related community programs to assure full coordination with such programs and to assure the provision of appropriate supplemental health, educational or social services for persons with developmental disabilities;

(6) protect the human rights of all persons with developmental disabilities, especially those without familial protection; and

(7) provide for interdisciplinary intervention and training programs for multihandicapped individuals.

Such annual State plan shall be initially submitted within one hundred and eighty days after the date of enactment of this Act.

(b) In order to be approved by the Secretary under this section, a State plan for the provision of services and facilities for persons with developmental disabilities shall—

(1) designate—

(A) a State planning and advisory council, which shall be responsible for submitting revisions of the State plan and transmitting such reports as may be required by the Secretary, and which shall include representatives of each of the principal State agencies and representatives of local agencies and nongovernment organizations and groups concerned with services for the developmentally disabled: *Provided,* That at least one-third of the membership of such council shall consist of representatives of consumers of such services;

(B) the State agency or agencies (except as provided in clause (C)) which shall administer and supervise the administration of the State plan, and if there is more than one such agency, the portion of such plan which each will administer (or the portion the administration of which each will supervise); and

(C) a single State agency as the sole agency for administering or supervising the administration of grants for construction, renovation, or modernization under the State plan;

(2) describe the quality, extent, and scope of services being provided or to be provided to meet the goals specified in subsection (a) of this section;

(3) describe (A) the quality, extent, and scope of services being provided, or to be provided, to persons with developmental disabilities under such other State plans for Federally assisted State programs as may be specified by the Secretary, which shall in any case in-

clude education for the handicapped, vocational rehabilitation, medical assistance, social services, maternal and child health, crippled children's services, and comprehensive health and mental health plans, and (B) how funds allotted to the State in accordance with section 302 will be used to complement and augment rather than duplicate or replace services and facilities for persons with developmental disabilities who are eligible for Federal assistance under such other State programs;

(4) provide for the maximum utilization of all available community resources including volunteers serving under the Domestic Volunteer Service Act of 1973 (87 Stat. 394) and other appropriate voluntary organizations;

(5) set forth policies and procedures for the expenditure of funds under the plan, which, in the judgment of the Secretary, are designed to assure effective continuing State planning, evaluation, and delivery of services (both public and private) for persons with developmental disabilities;

(6) contain assurances satisfactory to the Secretary that (A) the funds paid to the State under this title will be used to make a significant contribution toward strengthening services for persons with developmental disabilities in the various political subdivisions

of the State in order to improve the quality, scope, and extent of such services; (B) part of such funds may be made available to other public or nonprofit private agencies, institutions, and organizations; (C) such funds will be used to supplement and, to the extent practicable, to increase the level of funds that would otherwise be made available for the purposes for which the Federal funds are provided and not to supplant such non-Federal funds; and (D) there will be reasonable State financial participation in the cost of carrying out the State plan;

(7) provide that services and facilities furnished under the plan for persons with developmental disabilities will be in accordance with standards prescribed by regulations of the Secretary pursuant to this Act;

(8) provide such methods of administration, including methods relating to the establishment and maintenance of personnel standards and selection and advancement of personnel on a merit basis, as are found by the Secretary to be necessary for the proper and efficient operation of the plan (except that the Secretary shall exercise no authority with respect to the selection, tenure of office, and compensation of any individual employed in accordance with such methods);

(9) provide assurances that the State planning and

advisory council is assigned adequate personnel in order to insure that such council has the capacity to fulfill its responsibilities in the areas of planning, resource development, and program evaluation;

(10) provide that the State planning and advisory council shall periodically, but not less often than annually, review and evaluate the State plan and submit appropriate modifications to the Secretary for his approval;

(11) provide that the State agencies designated pursuant to paragraph (1) of this subsection will make such reports, in such form and containing such information, as the Secretary or the State planning and advisory council may from time to time reasonably require, and will keep such records and afford such access thereto as the Secretary finds necessary to assure the correctness and verification of such reports;

(12) provide that special financial and technical assistance shall be given to areas of urban or rural poverty in providing services and facilities for persons with developmental disabilities who are residents of such areas;

(13) describe the methods to be used to assess the effectiveness and accomplishments of the State in meet-

ing the needs of persons with developmental disabilities in the State;

(14) specify the maximum amount of, and the percentage of the State's allotment under section 302 for any year which is to be devoted to construction, renovation, or modernization of facilities, which percentage shall be not more than 10 per centum of the State's allotment or such lesser percentage as the Secretary may from time to time prescribe;

(15) provide reasonable assurance that adequate financial support will be available to complete the construction of, and to maintain and operate when such construction is completed, any facility the construction of which is assisted by funds made available under this title;

(16) if Federal funds are allotted for construction, renovation, or modernization under this title, outline a program of construction, renovation, or modernization of facilities for the provision of services for persons with developmental disabilities which—

(A) is based on a statewide inventory of existing facilities and survey of need;

(B) sets forth the relative need, determined in accordance with the regulations prescribed by the Secretary for the several projects included in the construction, renovation, or modernization program; and

(C) assigns priority to the construction, renovation, or modernization of projects, to the extent that financial resources available therefor and for maintenance and operation permit such priority, in the order of relative need, taking into account the requirement that any such construction, renovation, or modernization complies with any standards prescribed pursuant to the Architectural Barriers Act of 1968;

(17) provide for an opportunity for hearing before the State agency to every applicant for a construction, renovation, or modernization project;

(18) provide for such fiscal control and fund accounting procedures as may be necessary to assure the proper disbursements of, and accounting for, funds paid to the State under this title in accordance with regulations the Secretary shall prescribe;

(19) provide for the implementation of an evaluation system compatible with the system developed under section 309 of this Act by October 1, 1977;

(20) provide, to the maximum extent feasible, an opportunity for prior review and comment by the State planning and advisory council of all State plans in the

State which relate to programs affecting persons with developmental disabilities;

(21) provide that personnel assigned to the State planning and advisory council shall be solely responsible to such council;

(22) provide that all relevant information concerning any programs which may affect persons with developmental disabilities shall be made available by projects and State agencies to the State planning council; and

(23) contain such additional information and assurances as the Secretary may determine to be necessary to carry out the provisions and purpose of this part.

(c) The Secretary shall approve any State plan and any modification thereof which complies with the provisions of subsection (b) of this section. The Secretary shall not disapprove a State plan unless he has provided reasonable notice and opportunity for a hearing to the State.

WITHOLDING OF PAYMENTS

SEC. 305. (a) Whenever the Secretary, after reasonable notice and opportunity for hearing to a State planning and advisory council and a State agency or agencies designated pursuant to section 304 (b) (1) finds—

(1) that any such State agency or agencies are not complying with the provisions required by section 304

(b) to be included in the State plan, or with regulations of the Secretary;

(2) that any requirement set forth in an application submitted under section 304 and approved by the Secretary is not being or cannot be carried out with respect to the project for which such application was submitted; or

(3) that adequate funds are not being provided annually for the direct administration of the State plan, the Secretary may forthwith notify such State council and State agency or agencies that no further payments will be made from allotments under this title for any project or projects designated by the Secretary as being affected by the action or inaction referred to in paragraph (1), (2), or (3) of this subsection as the Secretary may determine to be appropriate under the circumstances.

(b) Whenever the State planning and advisory council finds that a State agency administering funds pursuant to the implementation design is failing to comply with such design, the State planning and advisory council shall notify the Governor and the Secretary, who may provide notice, conduct a hearing, and withhold payments pursuant to subsection (a) of this section.

PAYMENTS TO THE STATES FOR PLANNING, ADMINISTRATION AND SERVICES

SEC. 306. From each State's allotment for a fiscal year under section 302, the State shall be paid the Federal share of its expenditures incurred during such year under its State plan approved under this title. Such payments shall be made from time to time in advance on the basis of estimates by the Secretary of the sums the State will expend under the State plan, except that such adjustments as may be necessary shall be made on account of previously made underpayments or overpayments under this section.

REGULATIONS

SEC. 307. (a) The Secretary shall prescribe general regulations applicable to all the States to carry out the purposes of this title.

(b) (1) Regulations promulgated by the Secretary may be waived upon approval of an application submitted by a State for a project to be completed by two or more political subdivisions or public or nonprofit private agencies, or by a combination thereof, which is consistent with applicable law and regulations promulgated by the Secretary for such purposes to provide services to persons with developmental disabilities by combining funds received from other Federal, State, or local programs to the extent that such regulations would without such waiver impede the implementation of such project. Such waivers shall be reviewed annually by the Secretary and issued on a case-by-case basis and for a specified period of time, but in no case longer than thirty-six months. Renewal of such waivers may be granted only after a full evaluation of the impact of such waivers by the Secretary.

(2) The Secretary shall publish in the Federal Register the fact that an application for waiver under paragraph (1) has been submitted by a State, and he shall not approve or disapprove such application for a period of not less than sixty nor more than ninety days after the date of such publication.

NONDUPLIC[illegible]

SEC. 308. (a) In determining the amount of any payment for the construction, renovation, or modernization of any facility under a State plan approved under this title, there shall be disregarded (1) any portion of the costs of such construction, renovation, or modernization which are financed by Federal funds provided under any provision of law other than this title, (2) the amount of any non-Federal funds provided under any provision of law other than this title, and (3) the amount of any non-Federal funds required to be expended as a condition of receipt of such Federal funds.

(b) In determining the amount of any State's Federal share of expenditures for planning, administration, and services incurred by it under a State plan approved under this title, there shall be disregarded (1) any portion of such expenditures which are financed by Federal funds provided under any provision of law other than this title, and (2) the amount of any non-Federal funds required to be expended as a condition of receipt of such Federal funds.

EVALUATION OF DEVELOPMENTAL DISABILITIES SERVICES

SEC. 309. (a) (1) The Secretary, in consultation with the National Council, shall, by February 1, 1977, develop (A) a design of a comprehensive system for the evaluation of services provided to individuals with developmental disabilities and (B) a time-phased plan for the implementation by the States of such system which will specify a minimal evaluation system to be implemented by all States by October 1, 1977, and which will further specify phases of development leading to the establishment in each State of such comprehensive evaluation system. The comprehensive system shall provide guidelines and alternative methods for the development of State evaluation systems for federally supported services delivered within each State to individuals with developmental disabilities.

(2) Not later than February 1, 1977, the Secretary shall submit to the Congress a report on the evaluation system design developed pursuant to paragraph (1). Such

report shall include an estimate of the costs to the Federal Government and the States of developing and implementing such system.

(b) The Secretary, in consultation with the National Council, may make grants to, and enter into contracts with, public or private organizations or individuals to conduct feasibility studies to assist in developing the evaluation system required under subsection (a).

GRANTS FOR SPECIAL PROJECTS FOR SERVICES TO PERSONS WITH DEVELOPMENTAL DISABILITIES

SEC. 310. (a) For the purpose of making grants under this section for special projects and demonstrations (and research and evaluation connected therewith), there are authorized to be appropriated $18,500,000 for the fiscal year ending June 30, 1975, and for each of the two succeeding fiscal years.

(b) (1) The Secretary, after consultation with the National Council, shall make grants to States and public or nonprofit agencies and organizations to pay part or all of the cost of special projects and demonstrations (and research and evaluation in connection therewith) for (A) establishing programs which hold promise of expanding or otherwise improving services to persons with developmental disabilities (especially those who are disadvantaged or multihandicapped), and (B) for carrying out projects of special national significance including, but not limited to—

(i) demonstration projects for integrating services for the developmentally disabled population,

(ii) demonstration projects to coordinate and utilize all available community resources,

(iii) projects designed to improve the administration of, and the quality of care provided under, programs for individuals with developmental disabilities, and

(iv) projects to demonstrate new or improved techniques for the provision of services for such individuals.

(2) From the amount appropriated pursuant to subsection (a), the Secretary may reserve 30 per centum thereof for the purpose of making grants for projects described in subsection (b) (1) (B).

(3) Grants under this section may be used to support only the initial three years of any project or demonstration

(c) A copy of each application for a grant under this section shall be submitted by the applicant to the appropriate State planning and advisory council simultaneously with submission to the Secretary. The Secretary shall not approve such an application until the State planning and advisory council has had an opportunity, for a period of at least thirty days, to review and make comments on the application to the Secretary.

(d) Projects, or a component of any project funded under this section, shall not be eligible for funding under section 304 of the Rehabilitation Act of 1973 or section 303(a)(2) of the Public Health Service Act.

REPEAL

Sec. 311. Effective ninety days after the enactment of this Act, parts B and C of the Developmental Disabilities Services and Facilities Construction Act are repealed.

94TH CONGRESS
1ST SESSION

H. R. 4005

IN THE SENATE OF THE UNITED STATES

APRIL 14, 1975

Read twice and referred to the Committee on Labor and Public Welfare

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AN ACT

To amend the Developmental Disabilities Services and Facilities Construction Act to revise and extend the programs authorized by that Act.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SHORT TITLE

SECTION 1. This Act may be cited as the "Developmental Disabilities Amendments of 1975".

EXTENSION OF EXISTING AUTHORITIES THROUGH FISCAL YEAR 1975

SEC. 2. (a) Sections 122(b) and 131 of the Developmental Disabilities Services and Facilities Construction Act (hereinafter in this Act referred to as the "Act") are each amended by striking out "for the fiscal year ending June 30, 1974" and inserting in lieu thereof "each for the fiscal years ending June 30, 1974, and June 30, 1975".

(b) Section 137 (b) (1) of the Act is amended by striking out "and June 30, 1974" and inserting in lieu thereof ", June 30, 1974, and June 30, 1975".

EXTENSION OF DEMONSTRATION AND TRAINING GRANTS

SEC. 3. (a) Section 122 (b) of the Act (as amended by section 2) is amended by striking out "and" after "1973;" and by inserting after "1975" the following: "; $12,000,000 for fiscal year 1976; and $15,000,000 for fiscal year 1977".

(b) Section 124 of the Act is amended to read as follows:

"PAYMENTS

"SEC. 124. Payments of grants under section 122 shall be made in advance or by way of reimbursement, and on such conditions, as the Secretary may determine.".

SPECIAL PROJECT GRANTS

SEC. 4. Section 130 of the Act is amended to read as follows:

"SPECIAL PROJECT GRANTS

"SEC. 130. (a) The Secretary may make grants to public or nonprofit private entities for—

"(1) demonstration projects for the provision of services to persons with developmental disabilities who are also disadvantaged because of their economic status or the location of their residences,

"(2) technical assistance relating to services and facilities for persons with developmental disabilities, including assistance in State and local planning or administration respecting such services and facilities,

"(3) training of specialized personnel needed for the provision of services for persons with developmental disabilities or for research directly related to such training,

"(4) developing or demonstrating new or improved techniques for the provision of services to persons with developmental disabilities,

"(5) gathering and disseminating information relating to developmental disabilities,

"(6) coordinating, integrating, and using all available community resources for services to persons with developmental disabilities, and

"(7) improving the administration of, and the quality of services provided in, programs for such persons.

"(b) No grant may be made under subsection (a) unless an application therefor has been submitted to, and approved by, the Secretary. Such application shall be in such form, submitted in such manner, and contain such information, as the Secretary shall by regulation prescribe. The Secretary may not approve such an application unless the State in which the applicant's project will be conducted has a State plan approved under section [illegible]34.

"(c) The amount of any grant under subsection (a) shall be determined by the Secretary; and payments under such grants may be made in advance or by way of reimbursement, and at such intervals and on such conditions, as the Secretary finds necessary. In determining the amount of any grant under subsection (a) for the costs of any project there shall be excluded from such costs an amount equal to the sum of (1) the amount of any other Federal grant which the applicant has obtained, or is assured of obtaining, with respect to such project, and (2) the amount of any non-Federal funds required to be expended as a condition of such other Federal grant.

"(d) For the purpose of making payments under grants under subsection (a), there are authorized to be appropriated $15,000,000 for fiscal year 1976 and $15,000,000 for fiscal year 1977. Of the funds appropriated under this subsection for any such fiscal year, not less than 30 per centum of such funds shall be used for projects of national significance, as determined by the Secretary.

"(e) No funds appropriated under the Public Health

Service Act or under this Act (other than under subsection (d) of this section) may be used to make grants under subsection (a)."

STATE ALLOTMENTS

SEC. 5. (a) Section 131 of the Act is amended to read as follows:

"AUTHORIZATION OF APPROPRIATIONS FOR ALLOTMENTS

"SEC. 131. For allotments under section 132, there are authorized to be appropriated $40,000,000 for fiscal year 1976 and $50,000,000 for fiscal year 1977."

(b) Subsection (a) of section 132 of the Act is amended to read as follows:

"(a) (1) (A) In each fiscal year, the Secretary shall, in accordance with regulations and subparagraph (B) of this paragraph, allot the sums appropriated for such year under section 131 among the States on the basis of—

"(i) the population,

"(ii) the extent of need for services and facilities for persons with developmental disabilities, and

"(iii) the financial need,

of the respective States. Sums allotted to the States under this section shall be used in accordance with approved State plans under section 134 for the provision under such plans of services and facilities for persons with developmental disabilities.

"(B) The allotment of the Virgin Islands, American Samoa, Guam, and the Trust Territory of the Pacific Islands under subparagraph (A) of this paragraph in any fiscal year shall not be less than $50,000. The allotment of each other State in any fiscal year shall not be less than $100,000.

"(2) In determining, for purposes of paragraph (1) (A) (ii), the extent of need in any State for services and facilities for persons with developmental disabilities, the Secretary shall take into account the scope and extent of the services specified, pursuant to section 134 (b) (5), in the State plan of such State approved under section 134.

"(3) Sums allotted to a State in a fiscal year and designated by it for construction and remaining unobligated at the end of such year shall remain available to such State for such purpose in the next fiscal year (and in such year only), in addition to the sums allotted to such State in such next fiscal year; except that if the maximum amount which may be specified for construction (pursuant to section 134 (b) (15)) for a year plus any part of the amount so specified pursuant to such section for the preceding fiscal year and remaining unobligated at the end of such fiscal year is not sufficient to pay the Federal share of the cost of construction of a specific facility included in the construction program of the State developed pursuant to section 134 (b) (13), the amount specified pursuant to section 134(b) (15) for such preceding year shall remain available for a second additional year for the purpose of paying the Federal share of the cost of construction of such facility.

"(4) Of the amount allotted to any State under paragraph (1) for fiscal year 1975, not less than 10 per centum of that allotment shall be used by such State, in accordance with the plan submitted pursuant to section 134(b) (20), for the purpose of assisting it in developing and implementing plans designed to eliminate inappropriate placement in institutions of persons with developmental disabilities; and of the amount allotted to any State under paragraph (1) for each succeeding fiscal year, not less than 30 per centum of that allotment shall be used by such State for such purpose."

(c) Section 132(e) of the Act is repealed.

(d) (1) Subsection (b) of section 132 of the Act is amended by striking out "this part" each place it occurs and inserting in lieu thereof "the State plan".

(2) Section 134(b) (4) of the Act is amended by striking out "under this part" and inserting in lieu thereof "under section 132".

(3) Section 138 of the Act is amended by striking out "under this part" each place it occurs and inserting in lieu thereof "under section 132".

CONSTRUCTION PROJECTS

SEC. 6. (a) Sections 135 and 136 of the Act are repealed.

(b) Section 134 (b) of the Act is amended by striking out "and" after the semicolon at the end of paragraph (17), by redesignating paragraph (18) as paragraph (21), and by inserting the following new paragraphs after paragraph (17):

"(18) provide reasonable assurance that adequate financial support will be available to complete the construction of, and to maintain and operate when such construction is completed, any facility, the construction of which is assisted with sums allotted under section 132;

"(19) provide reasonable assurance that all laborers and mechanics employed by contractors or subcontractors in the performance of work on any construction project assisted with sums allotted under section 132 will be paid at rates not less than those prevailing on similar construction in the locality as determined by the Secretary of Labor in accordance with the Act of March 3, 1931 (40 U.S.C. 276a—276a-5, known as the Davis-Bacon Act); and the Secretary of Labor shall have with respect to the labor standards specified in this paragraph the authority and functions set forth in Reorganization Plan Numbered 14 of 1950 (15 F.R. 3176; 5

U.S.C. Appendix) and section 2 of the Act of June 13, 1934 (40 U.S.C. 276c);

"(20) contain a plan designed to eliminate inappropriate placement in institutions of persons with developmental disabilities, and to improve the quality of care and the state of surroundings of persons for whom institutional care is appropriate; and".

(c) The headings of sections 137 and 138 of the Act are each amended by inserting "CONSTRUCTION," after "PLANNING,".

(d) (1) Section 137 of the Act is amended (A) by striking out in subsection (a) (1) ", other than expenditures for construction,"; and (B) by amending subsection (b) to read as follows:

"(b) For purposes of subsection (a), the Federal share with respect to any State for fiscal year 1976 and for the next fiscal year shall be 75 per centum of the expenditures incurred by the State during such year under its State plan approved under section 134."

(2) Section 401 (h) of the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 is amended—

(A) by striking out "part C of title I or" in paragraph (1);

(B) by striking out "(A) for any project under part C of title I may not exceed 66⅔ per centum of the costs of construction of such project; and (B)" in paragraph (2); and

(C) by striking out "part C of title I or under" in paragraph (3).

(e) Section 140 of the Act is amended to read as follows:

"NONDUPLICATION

"SEC. 140. In determining the amount of any State's Federal share of the expenditures incurred by it under a State plan approved under section 134, there shall be disregarded (1) any portion of such expenditures which are financed by Federal funds provided under any provision of law other than section 132, and (2) the amount of any non-Federal funds required to be expended as a condition of receipt of such Federal funds."

GENERAL PROVISIONS AND CONFORMING AMENDMENTS

SEC. 7. (a) Section 134 of the Act is amended by adding at the end the following new subsection:

"(d) For purposes of any determination by the Secretary for purposes of subsection (b) (11) as to whether any urban or rural area is a poverty area, the Secretary may not determine that an area is an urban or rural poverty area unless—

"(1) such area contains one or more subareas which are characterized as subareas of poverty;

"(2) the population of such subarea or subareas constitutes a substantial portion of the population of such rural or urban area; and

"(3) the project, facility, or activity, in connection with which such determination is made, does, or (when completed or put into operation) will, serve the needs of the residents of such subarea or subareas."

(b) Part C of the Act is amended by adding after section 140 the following new section:

"RECOVERY

"SEC. 141. If any facility with respect to which funds have been paid under section 132 shall, at any time within twenty years after the completion of construction—

"(1) be sold or transferred to any person, agency, or organization (A) which is not a public or nonprofit private entity, or (B) which is not approved as a transferee by the State agency designated pursuant to section 134 or its successor; or

"(2) cease to be a public or other nonprofit facility for the mentally retarded or persons with other developmental disabilities, unless the Secretary determines, in accordance with regulations, that there is good cause for releasing the applicant or other owner from the obligation to continue such facility as a public or other nonprofit facility for the mentally retarded or persons with other developmental disabilities,

the United States shall be entitled to recover from either the transferor or the transferee (or, in the case of a facility which has ceased to be a public or other nonprofit facility for the mentally retarded or persons with other developmental disabilities, from the owners thereof) an amount bearing the same ratio to the then value (as determined by the agreement of the parties or by action brought in the district court of the United States for the district in which the facility is situated) of so much of such facility as constituted an approved project or projects, as the amount of the Federal participation bore to the cost of the construction of such project or projects. Such right of recovery shall not constitute a lien upon such facility prior to judgment."

(c) (1) Part A of the Act is amended to read as follows:

"PART A—GENERAL PROVISIONS

"DEFINITIONS

"SEC. 101. For purposes of this title:

"(1) The term 'State' includes Puerto Rico, Guam, American Samoa, the Virgin Islands, the Trust Territory of the Pacific Islands, and the District of Columbia.

"(2) The term 'facility for persons with developmental disabilities' means a facility, or a specified portion of a facility, designed primarily for the delivery of one or more services to persons with one or more developmental disabilities.

"(3) The terms 'nonprofit facility for persons with developmental disabilities' and 'nonprofit private institution of higher learning' mean, respectively, a facility for persons with developmental disabilities and an institution of higher learning which are owned and operated by one or more nonprofit corporations or associations no part of the net earnings of which inures, or may lawfully inure, to the benefit of any private shareholder or individual; and the term 'nonprofit private agency or organization' means an agency or organization which is such a corporation or association or which is owned and operated by one or more of such corporations or associations.

"(4) The term 'construction' includes construction of new buildings, acquisition, expansion, remodeling, and alteration of existing buildings, and initial equipment of any such buildings (including medical transportation facilities); including architect's fees, but excluding the cost of offsite improvements and the cost of the acquisition of land.

"(5) The term 'cost of construction' means the amount found by the Secretary to be necessary for the construction of a project.

"(6) The term 'title', when used with reference to a site for a project, means a fee simple, or such other estate or interest (including a leasehold on which the rental does not exceed 4 per centum of the value of the land) as the Secretary finds sufficient to assure for a period of not less than fifty years undisturbed use and possession for the purposes of construction and operation of the project.

"(7) The term 'developmental disability' means a disability attributable to mental retardation, cerebral palsy, epilepsy, autism, dyslexia, or a neurological condition of an individual found by the Secretary to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals, which disability originates before such individual attains age eighteen, which has continued or can be expected to continue indefinitely, and which constitutes a substantial handicap to such individual.

"(8) The term 'services for persons with developmental disabilities' means specialized services or special adaptations of generic services directed toward the alleviation of a developmental disability or toward the social, personal, physical, or economic habilitation or rehabilitation of an individual with such a disability; and such term includes diagnosis, evaluation, treatment, personal care, day care, domiciliary care, special living arrangements, training, education, sheltered employment, recreation, counseling of the individual with such disability and of his family, protective and other social and socio-legal services, information and referral services, follow-along services, and transportation services necessary to assure delivery of services to persons with developmental disabilities.

"STATE CONTROL OF OPERATIONS

"SEC. 102. Except as otherwise specifically provided, nothing in this title shall be construed as conferring on any Federal officer or employee the right to exercise any supervision or control over the administration, personnel, maintence, or operation of any facility for persons with developmental disabilities with respect to which any funds have been or may be expended under this title.

"RECORDS AND AUDIT

"SEC. 103. (a) Each recipient of assistance under this title shall keep such records as the Secretary shall prescribe, including (1) records which fully disclose (A) the amount and disposition by such recipient of the proceeds of such assistance, (B) the total cost of the project or undertaking in connection with which such assistance is given or used, and (C) the amount of that portion of the cost of the project or undertaking supplied by other sources, and (2) such other records as will facilitate an effective audit.

"(b) The Secretary and the Comptroller General of the United States, or any of their duly authorized representatives, shall have access for the purpose of audit and examination to any books, documents, papers, and records of the recipients of assistance under this title that are pertinent to such assistance.

"SHORT TITLE

"SEC. 104. This title may be cited as the Developmental Disabilities Services and Facilities Construction Act."

(2) Section 100 and part D of the Act and paragraphs (b), (l), and (m) of section 401 of the Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963 are repealed.

(d) Sections 137, 138, 139, 140, and 141 of part C of the Act are redesignated as sections 135, 136, 137, 138, and 139, respectively.

EFFECTIVE DATE

SEC. 8. The amendments made by sections 3, 4, 5, 6, and 7 shall take effect with respect to appropriations under the Act for fiscal years beginning after June 30, 1975.

REPORT AND STUDY

SEC. 9. (a) The Secretary of Health, Education, and Welfare (hereinafter in this section referred to as the "Secretary") shall, in accordance with section 101 (7) of the Act (defining the term "developmental disability") (as amended by section 7 of this Act), determine the neurological conditions of individuals which should be included as developmental disabilities for purposes of the programs authorized by parts B and C of the Act. Within six months of the date of enactment of this Act the Secretary shall make such determination and shall make a report thereon to the Congress specifying the neurological conditions which he determined should be so included, the neurological conditions which he determined should not be so included, and the reasons for each such determination. After making such report, the Secretary shall periodically, but not less often than annually, review the neurological conditions not so included as developmental disabilities to determine if they should be so included. The Secretary shall report to the Congress the results of each such review.

(b) (1) The Secretary shall contract for the conduct of an independent objective study to determine (A) if the basis of the definition of the developmental disabilities (as amended by section 7 of this Act) with respect to which assistance is authorized under such parts B and C of the Act is appropriate and, to the extent that it is not, to determine an appropriate basis for determining which disabilities should be included and which disabilities should be excluded from the definition, and (B) the nature and adequacy of services provided under other Federal programs for persons with disabilities not included in such definition.

(2) A final report giving the results of the study required by paragraph (1) and providing specifications for the definition of developmental disabilities for purposes of

parts B and C of the Act shall be submitted by the organization conducting the study to the Committee on Interstate and Foreign Commerce of the House of Representatives and the Committee on Labor and Public Welfare of the Senate not later than eighteen months after the date of enactment of the first Act making an appropriation for such study.

Passed the House of Representatives April 10, 1975.

Attest: W. PAT JENNINGS,
Clerk.

Senator RANDOLPH. Senator Stafford, would you comment, please?

Senator STAFFORD. Thank you very much, Mr. Chairman.

It is a privilege to work with you again on the developmental disabilities legislation this year, and add my welcome to yours to Mr. Kurzman, who will be the witness this morning, with his colleagues, in front of this subcommittee.

As you have pointed out, this is the first matter of business for this subcommittee, which is a pledge that we made at the conclusion of the last Congress, and maybe I should note for the record that as an accommodation to the administration, at their request, I introduced for them yesterday S. 1194, which is the administration bill in this area, so that that also can be in front of the subcommittee as we consider this important matter.

Senator RANDOLPH. Thank you, Senator Stafford. As you have indicated, we hope to have the cooperation of the administration. We cannot agree perhaps on all points; but we can move in concert for constructive legislation, and it is in that spirit that we begin the hearing. We commend you, Mr. Kurzman, for being present and helping us.

Proceed, if you will, please, to make your statement.

STATEMENT OF STEPHEN KURZMAN, ASSISTANT SECRETARY FOR LEGISLATION, DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE, ACCOMPANIED BY PETER FRANKLIN, SPECIAL ASSISTANT TO THE SECRETARY; AND FRANCIS LYNCH, DIRECTOR, DIVISION OF DEVELOPMENTAL DISABILITIES, OFFICE FOR HUMAN DEVELOPMENT

Mr. KURZMAN. Thank you very much, Mr. Chairman and Senator Stafford.

We deeply appreciate your warm welcome to us this morning, and congratulate the subcommittee on promptly getting back to this important act which we hope, as you do, will be promptly extended.

We appreciate the opportunity to have the chance to discuss it once again, to present our views on the Federal Government's role in this very important area of developmental disabilities, and to comment on both your bill, Mr. Chairman, S. 462, and the bill which the administration transmitted, and which Senator Stafford, as you noted, has been kind enough to introduce for us, S. 1194.

As you have pointed out in your review of this legislation, the authority for this program expired last June 30, and the House and Senate passed widely differing bills to extend it under the same number, H.R. 14215, but, regrettably, the differences between the two versions were such that they could not be resolved in conference before the end of the last Congress.

This year, as you have also noted, the same bill has been reintroduced in the Senate as S. 462, and although the new House bill, H.R. 4005, differs slightly from the bill passed by the House last year, the basic differences between the two bills remain.

We share, as I say, your desire, the subcommittee's desire, to see this impasse over the extension of this worthwhile program broken so that both we and the States can proceed with our planning free from the present uncertainty.

We have taken a new look at our own position, contained in the bills introduced during the last Congress—H.R. 12892 and S. 3011—and have developed a new bill which, we feel, is an improvement that can be accepted by both the House and Senate.

Senator Randolph. As you recall, Mr. Kurzman—I think Senator Stafford and I would like this in the record—I did not wish to criticize what happened last year. If it sounded so, I did not mean it to be.

I only recall that we never could even get to conference with the House because the Interstate and Foreign Commerce Committee had so much legislation other than this bill that they could not really come together with us in a conference.

This happens, and we all understand these problems.

Mr. Kurzman. Yes, Mr. Chairman.

In addition, Mr. Chairman, over the last few months we have examined carefully the very complex question of how to insure that the care provided by institutions serving developmentally disabled persons meets certain necessary standards.

I believe we all would agree that the standard of care provided in too many of our institutions today should be improved.

This subcommittee has attempted to address this problem in title II of S. 462, as have several Members of the House in such bills as H.R. 687. We strongly disagree with the approach taken in the title II portion of these bills.

Our Department has undertaken, over the past year, the massive effort of establishing and enforcing standards for the estimated 1,250 residential medical facilities funded under the medicaid program and providing services to the developmentally disabled. It is our judgment that implementation of legislation such as title II of S. 462 would have the untoward effect of not only duplicating and slowing the efforts already underway but, in fact, erasing the progress that has been made thus far.

We believe that our present efforts constitute a good first step that should not be duplicated. Rather, we should be looking ahead to see how we can best build upon the foundation already established. In a few minutes, I would like to discuss some of our ideas on this subject with you.

STATUS OF DEVELOPMENTAL DISABILITIES PROGRAM

First, I would like to describe briefly some of our current activities under the Developmental Disabilities program.

As you may know, the Developmental Disabilities program has been administered by the Division for Developmental Disabilities in the Rehabilitation Services Administration (RSA). When the Rehabilitation Services Administration was transferred at the beginning of last month from the Social and Rehabilitation Service to the Office for Human Development, the Division of Developmental Disabilities was transferred with it. We are now in the process of establishing a separate Office for Developmental Disabilities, with its Director reporting to the Assistant Secretary for Human Development.

The Developmental Disabilities program, as you know, is designed to achieve three basic purposes. The first is the development and improvement of planning capacity at State and local levels to utilize effectively the wide range of resources currently available to aid the developmentally disabled.

This Department alone is providing this year an estimated $800 million in such assistance from such agencies as the Office of Education, the Social and Rehabilitation Service, the Office for Human Development, the Health Services Administration, and the National Institutes of Health, and even more assistance is made available by State and local agencies.

One aim of this program, then, is to enhance the capability of State and local agencies to plan for the use of all these resources in a coordinated effective manner.

The second basic purpose of the program is to serve as a catalyst to stimulate the expansion of services for developmentally disabled persons at the State and local level.

The third purpose is the establishment of an integrated network within which services at the State and local levels will be coordinated.

In attempting to achieve these purposes, a major emphasis of the program is on the authority of the States to determine their own goals and the methods to achieve them. This flexibility has enabled the States to manage the program effectively, in our judgment.

STATE PROGRAMS

To describe the State programs, 55 States and territories have designated State planning and advisory councils and agencies to administer planning, services, and construction activities under this program.

Approximately $28 million, or 91 percent, of the $30.8 million expended this fiscal year under part C of the act has gone directly to the States and territories. The States have indicated, on the average, that they will use 73 percent of their funds for services, 25 percent for planning and administration, and 2 percent for construction.

A significant trend in the operation of the program has been the increased efforts by many States to deinstitutionalize developmentally disabled persons.

The States of North Carolina, Wisconsin, Washington, and California, in particular, have all emphasized this goal with success. It is generally agreed that returning the institutionalized individual to the community has, in the majority of cases, a good effect on his rehabilitation.

It is the policy of HEW to encourage deinstitutionalization where such a program is consistent with the capacities of the individuals concerned and where the home community can provide alternative services. We plan to continue this policy in our administration of programs for the developmentally disabled.

UNIVERSITY AFFILIATED FACILITIES FOR THE DEVELOPMENTALLY DISABLED

With regard to university-affiliated facilities for the developmentally disabled, the program presently provides Federal support for interdisciplinary training in institutions of higher learning. It is similar to activities supported in the maternal and child health program of title V of the Social Security Act.

Grants may be made to cover the costs of administering and operating demonstration facilities and training persons for personnel needed to render specialized services to persons with developmental disabilities. This year, $4,250,000 has been made available for training programs.

Among the professional disciplines trained in these facilities are medical personnel, dentists, nurses, speech and hearing therapists, nutritionists, physical therapists, occupational therapists, rehabilitation specialists, special educators, psychologists, social workers, and recreational specialists.

Each facility is encouraged to conduct a comprehensive program so that each discipline involved in the habilitation and rehabilitation of the developmentally disabled may be fully familiar with the contributions of the other disciplines.

ADMINISTRATION'S BILL

Now, Mr. Chairman, I would like to discuss briefly S. 1194, the bill proposed by the administration.

In general, our bill follows the format of title I of S. 462. However, as we have indicated on several occasions in the past, there are a number of features of title I of S. 462 which cause us serious concern.

Regrettably, because of the emphasis placed on title II, sometimes these differences seem to be lost, so we do stress them again.

Some of the major differences between S. 1194 and S. 462 are as follows:

ORGANIZATIONAL REQUIREMENTS

Our bill would not include, as does S. 462, a requirement that an Office of Developmental Disabilities be established in the Office of the Secretary.

As I noted earlier, we are already taking steps to establish such a separate office in the Office of the Secretary, making this provision of S. 462 unnecessary.

However, I cannot stress too strongly our strong opposition to any legislation containing rigid organizational requirements which limit the flexibility of our ever-growing and ever more complex Department in the management of its programs.

DEFINITION

Our bill, like S. 462, would include autism in the definition of developmental disabilities. However, unlike S. 462, it would not include specific learning disabilities in the definition, nor would it remove the requirement that disabilities covered under the act be neurological conditions.

As I stated in my testimony before this subcommittee last May 1, we do not object to these changes, provided that persons would still have to meet, in order to be covered under the developmental disabilities program, the three requirements listed in the definition. That the disability originate before age 18, that it can be expected to continue indefinitely, and that it constitute a substantial handicap as newly and more explicitly defined in S. 462.

We understand that, under this definition, those services which are provided under other programs, such as education, mental health, or vocational rehabilitation services, are not provided under this program.

The approach we are proposing will limit the program to those now being served in order to maintain the sharp focus of this program on its legitimate target group and will prevent the program's resources from being unduly diffused over a wide range of individuals as a result of an otherwise vague definition.

UNIVERSITY-AFFILIATED FACILITIES

Our bill would not include, as would S. 462, an authorization for grants for renovation and construction of university-affiliated facilities. These grants were needed in the original act to foster the initial construction of these facilities.

However, since many such facilities now exist, this Federal assistance is no longer needed. Moreover, this authorization has not been funded either by the administration or the Congress in the past few years, and we, therefore, see no justification for continuing it. Instead, we recommend that funds available for university-affiiliated facilities be used for demonstration and training grants for such facilities.

The authority for grants to university-affiliated facilities in the administration's bill would be similiar to that contained in current law, except that the emphasis of such projects would be focused on interdisciplinary training programs and other demonstration training projects and would not include the administration of demonstration facilities.

We disagree with the contention of this committee, as expressed in the committee report on H.R. 14215 during the last Congress, that the UAF program was created primarily to provide services to the developmentally disabled. We believe that the primary goal of this program has been, and should continue to be, to provide training for professionals who work with developmentally disabled persons. We believe that the satellite center program that would be established by S. 462 is not in line with this basic training objective of the UAF's.

DECLINING FEDERAL MATCH

We propose in our bill that the Federal matching share for State grants under the developmental disabilities program be gradually reduced from 70 percent in 1975 to 60 percent in 1976 and 50 percent in 1977. We believe it is appropriate for State and local governments to assume an increasingly greater degree of responsibility for service programs that affect their citizens, and that they should progressively increase their share of support for these programs.

NATIONAL AND STATE ADVISORY COUNCILS

The provisions in S. 1194 pertaining to the National Council on Services and Facilities for the Developmentally Disabled and the State planning and advisory councils would embody current law rather than the expanded provisions contained in S. 462.

We believe that such expanded functions are inappropriately assigned to such councils because they vest operational authority in the councils which would impede the effective administration of these programs by the responsible State and Federal officials.

FEDERAL APPROVAL OF CONSTRUCTION PROJECTS

The administration's bill would eliminate the requirement for Federal approval of construction projects under the State grant program. The deletion of this requirement is in accord with our objective of returning responsibility to State and local governments whenever it is appropriate to do so.

TIME LIMITATION FOR REGULATIONS PROMULGATION

S. 462 would require the Secretary to promulgate final regulations implementing title I within 90 days of the bill's enactment. Because of the need to consult with interested parties and to issue a notice of proposed rulemaking before those regulations can be put into effect, we regard such a time limitation as unrealistically short and as a serious impediment to the promulgation of effective regulations.

Moreover, this provision represents another potential limitation on the flexibility of the Department to manage its programs. Therefore, we have included no such provision in our bill.

EVALUATION OF SERVICES

Our bill would require the Secretary to develop, not later than February 1, 1977, a design for a comprehensive evaluation system to be implemented by the States in phases.

Each State receiving funds under this act would be required to implement the first phase of that system not later than October 1, 1977. We believe that such an approach to evaluation is more realistic and effective than the unworkable requirement in section 121 of S. 462 for the development by the Secretary within 18 months of an evaluation system and plan for implementation thereof which would be a model for State evaluation systems for all services delivered to persons with developmental disabilities.

SPECIAL PROJECTS AUTHORITY

Our bill would provide a special projects authority which would include authority for the Secretary to fund projects of special national significance in this field. The 10 percent set-aside for this purpose in the State grant portion of the act, which exists in present law and which would be continued under S. 462, would therefore be deleted and combined with other authorities.

Consonant with the aim of inducing greater State and local involvement, the administration bill proposes terminating Federal support for individual special projects after 3 years of initial assistance. This provision will give States and localities greater incentives to scrutinize these programs and evaluate their effectiveness.

In addition, our bill would provide that projects funded out of this special project grant authority could not receive funding under section 304 of the Rehabilitation Act of 1973 or section 303(a)(2) of the Public Health Service Act. These are the two authorities under which service projects are presently funded.

Since we are proposing to create a new project grant authority for the developmentally disabled to replace these present authorities, we feel that these authorities should not continue as a source of funding for such projects.

S. 462, on the other hand, would eliminate section 304 of the Rehabilitation Act as a funding source for these projects, but not section 303 of the Public Health Service Act.

We think that all three authorities should be combined under this act.

AUTHORIZATIONS

Lastly, our bill would provide for authorizations of appropriations which would correspond to the amounts set forth for these programs in the President's budget for fiscal year 1976. Thus, our bill would authorize the appropriation of a total of $160.9 million through 1977.

Of this amount, $12.5 million for special projects has already been appropriated for 1975 in Public Law 93-517, the Labor-HEW appropriations bill. The Senate bill, on the other hand, extends the program through 1979 with total authorizations of $710.7 million.

We believe that, in light of the many demands on the Federal budget and the severe Federal deficits which we are facing in the upcoming years, the authorizations in S. 462 are far too high.

QUALITY ASSURANCE

Now, Mr. Chairman, I would like to turn to the very complex subject of quality assurance in facilities providing care for developmentally disabled persons.

The point I would like to emphasize once again for the subcommittee is that our Department is presently undertaking a far-reaching effort to upgrade the quality of care provided to developmentally disabled persons in medical or rehabilitative residential institutions.

As you know, on January 17, 1974, we published regulations establishing extensive standards for intermediate care facilities for the mentally retarded (ICF-MR's), and we are now engaged in the major task of implementing them.

These standards, which we believe largely implement the same objectives as title II of the Senate bill, relate to habilitative services, medical care, fire safety, physical environment and sanitation. They aim at assuring that residents of ICF-MR's receive an array of services keyed to their individual needs so that they may reach their maximum potential.

These regulations will have a substantial impact on the well-being of the many thousands of developmentally disabled persons who reside in such facilities.

The ICF-MR regulations, which are based on the recommendations of the Accreditation Council for Facilities for the Mentally Retarded of the Joint Commission on Accreditation of Hospitals, were issued under title XIX of the Social Security Act. Consequently, they apply to all ICF-MR's certified for Medicaid reimbursement. Implementation of the standards must be completed by March 1977.

This phasein period will allow many facilities to complete the expensive and time-consuming renovations which the regulations will necessitate. Each intermediate care facility approved to participate in medicaid must, no later than March 1975, have a detailed plan for meeting the requirements by 1977. If it does not progress in accordance with that plan, it will be barred from continued participation in the medicaid program.

Our experience in developing and implementing these regulations indicates that the level of detail of the standards represents the limit that realistically can be expected of the network of facilities serving the developmentally disabled.

While we recognize that the ICF-MR standards alone will not succeed in raising the quality of care in all our institutions serving the developmentally disabled, we believe that to go beyond these standards in the way that title II of S. 462 proposes to do would be to make unrealistic demands on the thousands of agencies and facilities involved. Such demands could result in a major disruption in the delivery of services to the developmentally disabled and create considerable confusion and uncertainty for, and in many cases termination of services provided by, individual facilities and agencies.

Last year, we prepared a rather detailed analysis of title II of the Senate bill, which is attached to the letter from the Secretary transmitting to the Congress our new bill to extend the Developmental Disabilities Act. A copy of that letter, with the attached paper, has been forwarded to each member of the subcommittee, and with your permission, Mr. Chairman, I would ask that it be printed in full with my remarks, if I may.

Senator **RANDOLPH**. It will be printed in the record at the conclusion of your testimony.

Mr. **KURZMAN**. While our objections to that title are described in detail in the paper, I would like to cite just a few examples of the disastrous results which would ensue from enactment of that legislation.

1. Section 204 authorizes the Secretary to make grants to assist States in bringing publicly operated and federally assisted residential or community facilities and agencies into compliance with the title II standards.

While the precise number of facilities affected by title II is unknown, for the purposes of preparing cost estimates, we have estimated that at least 6,000 facilities are involved. A conservative estimate of the amount needed by each residential institution over 5 years to bring itself into compliance with the title II standards would be $1 million.

Thus, at a minimum, the cost of bringing each facility into compliance with these standards would be $6 million. This total would be reduced to approximately $1.250 billion if only residential facilities which provide medical services received the financial assistance; however, this lower figure does not take into account thousands of facilities providing personal care and thousands of community service agencies, all of which would be affected by title II.

2. Section 205 of S. 462 would permit "Federal assistance payments authorized under Federal law" to "publicly operated or assisted facilities for the developmentally disabled only if" the facility provides evidence that such payments have not resulted in nor will result in any decrease in per capita State and local expenditures for services for the developmentally disabled which would otherwise be available to the facility.

While we do not object to the concept of maintenance of effort requirements, we believe that perpetual maintenance of effort obligations are undesirable. Moreover, we object to this particular provision because we feel it is inequitable to hold an individual facility responsible for assuring that State payments to the facility do not decrease.

In addition, it is possible that this section would not accomplish its desired effect since there is no sanction to be applied against States who fail to maintain total current expenditures for the developmentally disabled.

3. Section 206 of S. 462 would authorize the withholding of all Federal payments, whether direct or indirect, to any program of community care or residential facility for individuals with developmental disabilities unless it meets the standards established by title II within 5 years.

Our principal concern with this provision is that it could result in a major disruption in the delivery of services to the developmentally disabled and to others in facilities which receive Federal reimbursement for services rendered.

This provision would create considerable confusion and uncertainty for both State, and individual facilities and agencies which are currently in the midst of planning for and implementing the existing Federal ICF standards, but I have referred to the ones we have already put into place under already existing provisions of law.

In addition, because section 206 would apply to facilities receiving medicare and medicaid reimbursement, it could create hardships for the nondevelopmentally disabled populations receiving services in such facilities, since it could result in a facility's loss of medicare or medicaid funds for all of its patients.

Lastly, this provision, since it would apply to so many different facilities and so many sources of Federal funds, would create an overwhelming administrative burden, since residential and community facilities and programs receive Federal funds from a variety of State and local, as well as Federal, agencies.

Effective enforcement of the withholding of Federal funds, particularly enforcement with respect to funds paid indirectly as a result of revenue sharing, would require a massive monitoring and tracking effort, involving a great increase in Federal regional manpower.

4. Section 211 of S. 462 requires individual written habilitation plans to be developed and modified at "frequent" intervals on behalf of each developmentally disabled person who is residing in a residential facility, community facility, and agency to which the title II standards apply.

We estimate that the cost for an initial evaluation of an individual would be $400, based on the services of a four-person basic team working one-half of a day.

Quarterly evaluations would be an estimated $100 each. The first-year cost for the habilitation plan would therefore be an estimated $700 per person, or a total of $5.6 billion, based on an estimated population of 8 to 8.5 million persons.

This estimate of the affected population is considered conservative; other estimates have placed the target population as high as 20 million.

Not only would the cost of section 211 be prohibitive, but it would require measurement in areas where assessment is difficult to make, such as affective and cognitive development. There are only a few personnel trained well enough to make the sort of assessments required under this section.

5. Section 212 would require that each developmentally disabled person served by a facility or agency be assigned a program coordinator responsible for implementation of the person's individual written habilitation plan. For an estimated population of 8 million persons, 1.3 million highly trained health personnel would have to be available to serve as program coordinators.

Moreover, as I indicated earlier, these personnel would have to be exceptionally well trained in order to perform the functions required by title II. This number of highly trained personnel is simply not available.

Mr. Chairman, I think you can see that the resources in terms of manpower and money that would be needed to enable the many facilities and agencies affected by title II to comply with the requirements of that title are not available.

I greatly fear that the result of placing such clearly unrealistic demands on these facilities would only result in their refusal to provide any care at all for developmentally disabled persons.

Such a result would, in our opinion, be clearly undesirable and counter to the objectives that both the Congress and the administration share, which is improved care for these persons.

We believe that we should be looking to the next step to be taken beyond the existing ICF quality assurance program. We certainly agree with the subcommittee on that subject.

It is our judgment that the next initiative in quality assurance needs to focus on the residents themselves, to insure that they are receiving and responding to effective programs of care that are helping them to develop and to reach their potential as fully as possible.

We refer to this approach as the outcome approach of quality assurance, wherein we seek to measure a facility's performance by the results it produces with its residents.

While we have long been committed to such an "outcome" approach—indeed, this idea received considerable discussion in the Department at the time the ICF regulations were being developed—we feel there is a lack in the technological ability to implement it.

However, recent developments in the developmental disabilities field—some of which occurred in projects sponsored by HEW—hold promise that we can move in this direction.

Unfortunately, technology will not allow us to adopt national outcome standards such as those proposed by part B of title II of S. 462, but an outcome approach does constitute the next necessary step in our efforts to raise the standard of care for the developmentally disabled.

We believe we should have authority to move in this direction as the approach is validated.

For the reasons stated above, we strongly oppose the enactment of S. 462 and urge, instead, the prompt enactment of the administration's bill as an effective instrument for meeting the needs of the developmentally disabled population.

This concludes my statement, Mr. Chairman. My colleagues and I will be pleased to answer any questions you and your subcommittee members may have.

Senator **Randolph**. Thank you, Mr. Secretary.

You are, of course, not a newcomer to this subject, and neither are the members of the subcommittee. We have worked with each other and sometimes at odds with each other, but I never have thought of it as a polarization. We have expressed our viewpoints very vigorously, as you have done this morning in your statement.

I do not want to be critical just for the sake of criticism, but I do want to tell you that the statement that you have presented was provided to our subcommittee only this morning. There was no opportunity for us to distribute it to the members of the subcommittee who might not be able to attend our hearing but who might have questions that they would want to present to you and to your associates, Mr. Franklin and Mr. Lynch.

I was unable to review the statement. I attempted to listen very carefully as you spoke, and have some questions to ask now. However, after further review, I am sure that I will have more comments and questions, which I will send in writing for your response.

Would that be agreeable?

Mr. KURZMAN. Absolutely, Mr. Chairman.

Let me apologize for not complying with the committee's rule. We have very strict orders from Secretary Weinberger to comply with the committee's rule in this regard.

We have great difficulty, as you know, in doing so, partially because of the demands made on the Department to testify on a great variety of subjects, and partially I must say because of the complexity of the Federal Establishment in making sure that all parts of our Department and the Federal Government get to see a statement and make input to it, which is only for our people who have related functions, particularly in a field such as ours.

However, we will be happy to answer any questions that the subcommittee wants to put to us in writing. (See pp. 460-487.)

Senator RANDOLPH. I do know these problems of complexity, but it is worth our stating once again that it is very helpful when you can have this information ahead of time.

Senator Stafford knows that on our Committee on Public Works, if witnesses do not send their testimony to us 24 hours in advance of the hearing, we do not allow them to testify. There may be reason, of course, to modify that rule in certain instances; but we are constantly faced with the fact that people have known for 2 or 3 weeks that they were to testify on a certain date but have not provided us with statements in advance. It is a difficult situation in which you, of course, find yourself, and also one in which we are not completely at ease.

Now, to get on to the questions.

We know that today we are in a recession. Our faltering economy is a matter for concern not only at the Federal level but at the State level.

I have talked with some 15 Governors since this Congress has begun—Appalachian Governors, for example. Senator Stafford and I have been meeting with Governors who have talked about programs of highway construction throughout the country. In addition, I have been talking with many of the mayors of the communities in West Virginia at the recent convention here. I am led to believe that this is a difficult time to ask the States or the other political subdivisions to increase their share of the programs that we have been mandating.

I am sure you possibly will agree with that statement.

Mr. KURZMAN. Mr. Chairman, these are difficult times for our Nation, indeed for the entire world, economically I think, as Secretary Weinberger has said in answer to a similar question before other subcommittees on other Administration proposals made to shift a greater share of the cost of some of our shared Federal-State matching programs from the Federal Government to the States, as in the developmental disabilities program, it is a question of relative misery we are talking about.

We think both the Federal and State and local levels—all levels of government—are hard pressed, as is the economy in general, but that the level of deficits being experienced and likely to be experienced by Federal Government is of a much higher order proportionately, certainly in absolute terms, than that faced by the States.

In addition, in the President's program, there is a proposed increase designed, in part, to meet additional costs that the States and localities would experience through increased fuel and other energy costs. We think that in many States the situation simply is not as great as it appears to be economically for the Federal Government.

Senator RANDOLPH. Mr. Kurzman, I am entirely bipartisan, and I know I do not have to talk on these subjects with Bob here. I think that the President has said that he would not sign into law new programs which were enacted by the Congress, even if they were programs that he himself thought were important.

Am I wrong in that statement?

I may have a reason to modify it, but I believe he said that he looked with disfavor upon new programs as we go into this Congress.

Mr. KURZMAN. That is my understanding, Mr. Chairman.

Senator RANDOLPH. Is that your understanding?

Now, that leads me to the question.

Is this a new program?

Mr. KURZMAN. No; Mr. Chairman. I would say much like two dozen other programs which expire this June 30, or have expired in prior years, the administration has requested the extension of those programs then.

Senator RANDOLPH. Then why do you propose a cutback in the Federal matching share? Programs for handicapped persons are often enacted because neither the State nor local level is able to do the job or give priority to programs for handicapped persons.

Mr. KURZMAN. That is my understanding of the origin of the program.

Senator RANDOLPH. I am disappointed and frustrated when the items that are cut at the Federal level are those that help the handicapped people and elderly people.

So, as we consider this legislation, we are trying to give equal opportunities to the handicapped population in the United States of America.

We have tried to bring these services to the handicapped individuals in the States, for it appears that State and local governments are unable to provide them.

So I am not sure that this is the time when we ought to cut back on the Federal share; certainly that is a matter for us to consider.

Do you feel there should be a cutting back on the Federal share, regardless of what the States and local communities can do?

Mr. KURZMAN. Mr. Chairman, I suppose I would have to say I would disagree with the characterization of what we are proposing as a cutback.

We are proposing to spend the same amount of money that we are currently spending from the Federal Treasury on this program. What we are proposing is that the proportions change in the future, and that States contribute a larger amount to the same projects than they are now, but not to reduce the amount the Federal Government provides for it.

I should point out that we are talking in the realm of a Federal budget, as the President has proposed it, for fiscal year 1976 which would increase HEW's total spending for the vulnerable groups that we serve—the aged, the handicapped, children, the ill—from almost approximately $111 billion to approximately $119 billion.

What we propose is not a cut but a slowing in the rate of increase of our Department overall. If what we propose is not adopted, the rate of increase would be more in line with the approximately 17 percent we have been experiencing each year in the prior 10 years or so, and would increase the total another $8 billion, which would bring it up to about $127 billion.

So we are not talking about a cut in any absolute terms. We are talking about a proposed slowing in the rate of increase. A very large proportion of the HEW budget, as proposed by the President, would go to the benefit of the handicapped, not all, obviously, under developmental disabilities program, but we are estimating a total expenditure, as I have said in the prepared statement, for this target group in the range of $800 million, taking all our programs into account, and we are not proposing in any way to cut that in fiscal 1976.

Senator RANDOLPH. You proposed in your statement, on page 7, that under this specific program the Federal share would decrease from 70 percent in 1975 to 60 percent in 1976 and then 50 percent in 1977.

You indicate that these States, of course, and local entities of government should increase their participation.

I think that would be a Federal cutback.

From your standpoint, that might not be indicative of an actual cutting of program, but it seems to me that percentage decrease would so indicate.

I have no desire to take up too much time, so I will turn the questioning over to Senator Stafford. I might have a further question after he has concluded.

Senator STAFFORD. Thank you very much, Mr. Chairman.

I have in mind the possibility that we might wish to submit questions in writing to the Department to Mr. Kurzman in the interest of saving time.

But I do have a few questions that I would like to present to you at this time.

My first one is, what do you believe, Mr. Kurzman, the Federal role is in insuring that rights of individuals in residential or community facilities are being protected?

Mr. KURZMAN. Senator Stafford, our role, I think, as is exemplified in the ICF–MR regulations, which are now in place and being enforced, is to set realistic enforceable standards, to require the States to conduct the kinds of surveys necessary within the facilities in those States and advise us as to the outcome of those surveys, to enforce through the States and under the medicaid program in the case of individual facilities which fail to meet those standards, or to meet the timetables for planning to meet those standards, by withholding the Federal funds, as we have done in the case of the skilled nursing facilities.

In some instances, it is necessary to enforce by using the Federal courts. As you know, we have brought lawsuits against the State of Pennsylvania under the ICF–MR regulations, and I think that is a primary function.

I would be happy to have Peter Franklin amplify if I have not covered it all.

Mr. Franklin. Senator Stafford, I would like to add just one point that we must continue to improve the State of the art after addressing the needs of the developmentally disabled.

I would like to amplify one thing Mr. Kurzman mentioned in his testimony.

This is to look at outcome measures. We are just beginning now to break through and be able to look at the impact directly on a patient or resident of a facility or a program. Our regulations to date, and the statutes, too, very much look at the capacity of a facility to deliver a certain service to an individual, not of a service as it directly impacts on the individual, and the progress of the individual. We must become much more patient centered, and we are very actively pursuing this now.

Senator Stafford. On page 15 of your statement, Mr. Kurzman, you used figures in connection with patient ratio, requirement for a coordinating on the basis of 1 to 6, and this Senator's understanding is that in the State of California, where a system like this is currently working, the ratio at worst is 1 to 40, and in some instances 1 to 120, making an average of 1 to 85.

We wonder where you got your figures.

Mr. Franklin. Senator Stafford, Mr. Kurzman asked me to try to respond to this.

We got our figures by talking to the HEW staff and the Social Rehabilitation Service and the Public Health Service, and estimating what it would take to implement what is required of a coordinator under S. 462, so it requires quite a few skills.

Such as financial skills, social skills, educational skills.

Therefore, it would take a highly trained person to pay the level of attention we think it would require to address all these adequately for a developmentally disabled person, so that the ratio that we have proposed we believe is appropriate.

Now, certainly you could expand the ratio, as California has done, but to meet these needs I would have to say that would be totally inadequate to fulfill what we at least thought we understood was the intent of the people who wrote the bill.

Senator Stafford. If we understand each other, then your position is that the ratio of 1 coordinator to 40 patients would be unrealistic and unworkable?

Mr. Franklin. Yes, sir, that is our position.

Senator Stafford. Have you been aware of the California program?

Mr. Franklin. Only in general, sir.

I was in California several weeks ago and talked to some of their top health people in State and county government, and I am aware of what is going on. But to deal with that level of ratio on an ongoing basis, the amount of hours they are able to spend with a person in a

40-hour week would be just 1 hour, which would mean just one meeting with the educational assistant for the individual, yet the needs of the individual in as comprehensive a program as this far exceeds 1 hour a week.

Senator STAFFORD. Did you talk with any of the California people in ascertaining from them whether they believe their program is working or not working effectively?

Mr. FRANKLIN. I got different opinions from them.

It is better than nothing, sir, certainly. And it is very important to have proper support, but to say that this was totally adequate to meet the needs of the people, sir, I know of no one out there who would support that, and certainly we do not support it.

Senator STAFFORD. Thank you.

To get back Mr. Kurzman, to your statement, on page 8, at the top of the page, you say that:

> We believe that such expanded functions are inappropriately assigned to such councils because they vest operational authority in the councils which would impede the effective administration of these programs by the responsible Federal and State officials.

This is under the subject, "National and State Advisory Councils."

Could you detail for us the functions incorporated in S. 462 which apply especially on a State level?

Mr. KURZMAN. If you will give me just a moment.

Senator STAFFORD. If it will save time, we could ask you to respond to it in writing.

Mr. KURZMAN. I would much prefer to do that. (See p. 461)

I would say, in general, we believe for input in many of our programs, particularly ones of this sort which are designed to be gap filling and coordinating and planning programs, advisory councils at the local level can have a very important function, but we think that it is also a mistake, when we hear this constantly—as I am sure you do from State and local government officials—to diffuse the operating responsibility away from the government officials.

They are elected and appointed to do the job, and we think they should have the responsibility for carrying it out. They should get the advice of citizens, and the advisory council is certainly an acceptable way to do it. We propose that that feature of the act be continued, but we would object to giving them what we think of as operating responsibilities.

Taking a look at the subsections, I can pick off at least three of the subsections while I am sitting here, and if we may amplify this in writing, I would appreciate it.

Subsection (b)(1) on page 35 of the bill imposes upon the State planning council the requirement to develop and prepare the State plan required by section 114.

Again, we would have no objection to having an input in the plan, but I do not know whether it is good policy to shift from the State agency the responsibility for the actual preparation of that plan.

Senator STAFFORD. That is giving States a greater participation in the whole program, is it not?

Mr. KURZMAN. I think our understanding, Senator, is that this would take away from the State official and give it to the planning council, which is not all State officials but includes the public citizens as well.

I think it is not a question of State versus local or State versus Federal. Certainly we agree that the State ought to have a key role here, and we always maintain this on the basically operated authorities.

It is just a question of the State level—should it be in the hands ultimately of the last order of the public officials, the Governor's representatives? I think that is where we would recommend to you that it be.

Subsection (3) would call for the council establishing priorities for the distribution of funds for programs for persons with developmental disabilities within the State.

Again, those authorities, we think, ought to be established by Government officials and not by the council.

Finally, subsection (4) calls for a review and comment on all State plans in the State which relate to programs affecting persons with developmental disabilities.

Again, as in the case of subsection (1), it is vesting authority in a nongovernmental body which we think ought to remain with the governmental body.

Senator STAFFORD. Thank you, Mr. Kurzman.

If you have a further elaboration on the question you wish to make in writing, we would be glad to receive it. We would ask that they be sent up here as expeditiously as possible so we may consider them on a timely basis within the context of our own plans.

I think I would conclude at this point by saying I do think you have done a very good job as advocate of the Department, and on behalf of the Department's bill in presenting the Department's reaction to the bill which the chairman, Senator Randolph, and I and others have introduced, which is also in front of the committee.

It is my hope that we can work out differences and reach a bill which both the administration and this subcommittee can support.

I suppose, Mr. Chairman, it ought to be almost off the record, but I cannot help but reflect that the former Under Secretary, Frank Carlucci, used to take part in these deliberations, and then he left the Department to resume his career as a diplomat and became Ambassador to Portugal.

I wonder now if he sometimes does not wish he were back here dealing with the complexities of HEW instead of the complexities of Portugal.

Mr. KURZMAN. I do not know about that, Senator Stafford, but I can say we miss him very much at the Department.

Senator RANDOLPH. Thank you very much, Senator Stafford.

It is thought that some of the money that may have been better used for Federal projects and programs to bring services to handicapped persons has gone into travel expenditures.

Would you be able to give us some breakdown in writing of the travel costs that have been involved as you have administered these programs?

I am not saying this as a direct criticism of you, but expenditures for travel are being questioned by committees here on the Hill, and properly so. Sometimes travel takes dollars away from services.

Do you understand?

Mr. KURZMAN. Yes, Mr. Chairman, I do. And we have been asked that question on other subcommittees, and we will be happy to supply that for the record.

I assume you mean both at the State as well as the Federal level?

Senator RANDOLPH. Oh, yes, indeed.

Mr. Kurzman, Senator Stafford and I, as we have indicated, will have questions which will be directed to you for response by letter.

Senator Harrison Williams, the chairman of this committee, has asked that I say to you that he will also, in his own right as an individual Senator and as chairman of the committee, have certain questions directed to you for response by writing.

Mr. KURZMAN. We will be happy to answer those for the record, Mr. Chairman.

Senator RANDOLPH. We thank you, Mr. Kurzman, and Mr. Franklin and Mr. Lynch.

We look forward to a joint effort in enacting legislation which will benefit developmentally disabled persons. I hope that, even though there are differences between us, we can modify them and not lose the constructive contributions that either the administration or the Congress can make. It is the responsibility of all of us to see that, through legislation and the implementation of the law, these people are given opportunities so that they can become as independent as possible and contribute to this society, which belongs to us all.

Mr. KURZMAN. Thank you very much, Senator Randolph and Senator Stafford.

[The prepared statement of Mr. Kurzman with accompanying responses to written questions submitted by Senators Stafford, Williams, Javits, and Mondale, and additional pertinent material supplied for the record, follow:]

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

STATEMENT

OF

STEPHEN KURZMAN

ASSISTANT SECRETARY FOR LEGISLATION

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

BEFORE THE

SUBCOMMITTEE ON THE HANDICAPPED

COMMITTEE ON LABOR AND PUBLIC WELFARE

UNITED STATES SENATE

TUESDAY, MARCH 18, 1975

INTRODUCTION

Mr. Chairman and members of the Subcommittee, it is a pleasure to appear before you once again to discuss our views on the Federal Government's role in the developmental disabilities program and to present our comments regarding S. 462, the "Developmentally Disabled Assistance and Bill of Rights Act."

As you know, the authority for the Developmental Disabilities program expired on June 30, 1974. The House and Senate passed widely differing bills to extend this program during the last Congress under the same number, H.R. 14215, but the differences between the two versions were such that they could not be resolved in conference. This year, the same bills have been [illegible]ntroduced as H.R. 4005 and S. 462, and the differences between them still remain.

I am sure you can understand our desire to see the impasse over the extension of this worthwhile program broken so that both we and the States can proceed with our planning free from the present uncertainty. We have taken a new look at our own position, contained in two bills introduced during the last Congress (H.R. 12892 and S. 3011), and have developed a new bill which, we feel, is an improvement that can be accepted by both the House and Senate. Our bill has been introduced, at our request, by Senator Stafford as S. 1194.

In addition, Mr. Chairman, over the last few months we have examined carefully the very complex question of how to ensure that the care provided by institutions serving developmentally disabled persons meets certain necessary standards. I believe we would all agree that the standard of care provided in too many of our institutions today should be improved. This Subcommittee has attempted to address this problem in Title II of S. 462, as have several members of the House in such bills as H.R. 687. We strongly disagree with the approach taken in these bills.

Our Department has undertaken over the past year the massive effort of establishing and enforcing standards for the 1,250 residential medical facilities funded under the Medicaid program. It is our judgment that implementation of legislation such as Title II of S. 462 would have the untoward effect of not only duplicating and slowing the efforts already underway, but in fact erasing the progress that has been made thus far. We believe that our present efforts constitute a good first step that should not be duplicated. Rather, we should be looking ahead to see how we can best build upon the foundation already established. In a few minutes I would like to discuss some of our ideas on this subject with you.

Status of Developmental Disabilities Program

First, however, I would like to describe briefly some of our current activities under the Developmental Disabilities program. As you may know, the Developmental Disabilities program has been administered by the Division for Developmental Disabilities in the Rehabilitation Services Administration (RSA). When the Rehabilitation Services Administration was transferred at the beginning of last month from the Social and Rehabilitation Service to the Office for Human Development, the Division for Developmental Disabilities was transferred with it. We are now in the process of establishing a separate Office for Developmental Disabilities, with its Director reporting to the Assistant Secretary for Human Development.

The Developmental Disabilities program, as you know, is designed to achieve three basic purposes. The first is the development and improvement of planning capacity at State and local levels to utilize effectively the wide range of resources currently available to aid the developmentally disabled. This Department alone is providing this year an estimated $800 million in such assistance from such agencies as the Office of Education, the Social and Rehabilitation Service, the Office for Human Development, the Health Services Administration, and the National Institutes of Health, and even more assistance is made available by State and local agencies. One aim of this program, then, is to enhance the capability of State and local agencies to plan for the use of all these resources in a coordinated, effective manner.

The second basic purpose of the program is to serve as a catalyst to stimulate the expansion of services for developmentally disabled persons at the State and local level. The third purpose is the establishment of an integrated network within which services at the State and local level will be coordinated. In attempting to achieve these purposes, a major emphasis of the program is on the authority of the States to determine their own goals and the methods to achieve them. This flexibility has enabled the States to manage the program effectively.

State Programs

Fifty-five States and Territories have designated State Planning and Advisory Councils and agencies to administer planning, services, and construction activities under this program. Approximately $28 million, or 91%, of the $30.8 million expended this fiscal year under Part C of the Act has gone directly to the States and Territories. The States have indicated, on the average, that they will use 73% of their funds for services, 25% for planning and administration, and 2% for construction.

A significant trend in the operation of the program has been the increased efforts by many States to deinstitutionalize developmentally disabled persons. North Carolina, Wisconsin, Washington, and California, in particular, have all emphasized this goal with success. It is generally agreed that returning the institutionalized individual to the community has in the majority of cases a good effect on his rehabilitation. It is the policy of HEW to encourage deinstitutionalization where such a program is consistent with the capacities of the individuals concerned and where the home community can provide alternative services. We plan to continue this policy in our administration of programs for the developmentally disabled.

University-Affiliated Facilities for the Developmentally Disabled

The program presently provides Federal support for interdisciplinary training in institutions of higher learning. It is similar to activities supported in the Maternal and Child Health program. Grants may be made to cover the costs of administering and operating demonstration facilities and training programs for personnel needed to render specialized services to persons with developmental disabilities. This year $4,250,000 has been made available for training programs.

Among the professional disciplines trained in these facilities are medical personnel, dentists, nurses, speech and hearing therapists, nutritionists, physical therapists, occupational therapists, rehabilitation specialists, special educators, psychologists, social workers, and recreational specialists. Each facility is encouraged to conduct a comprehensive program so that each discipline involved in the habilitation and rehabilitaton of the developmentally disabled may be fully familiar with the contributions of the other disciplines.

Administration's Bill

Now, Mr. Chairman, I would like to discuss briefly S. 1194, the bill proposed by the Administration. In general, our bill follows the format of Title I of S. 462. However, as we have indicated on several occasions in the past, there are a number of features of Title I of S. 462 which cause us serious concern. Some of the major differences between S. 1194 and S. 462 are as follows:

Organizational Requirements

Our bill would not include, as does S. 462, a requirement that an Office of Developmental Disabilities be established in the Office of the Secretary. As I noted earlier, we are already taking steps to establish such a separate office in the Office of the Secretary, making this provision of S. 462 unnecessary. However, I cannot stress too strongly our strong opposition to any legislation containing rigid organizational requirements which limit the flexibility of the Department in the management of its programs.

Definition

Our bill, like S. 462, would include autism in the definition of developmental disabilities. However, unlike S. 462, it would not include specific learning disabilities in the definition, nor would it remove the requirement that disabilities covered under the Act be neurological conditions. As I stated in my testimony before this Subcommittee last May 1, we do not object to these changes provided that persons would still have to meet, in order to be covered under the Developmental Disabilities program, the three requirements listed in the definition: that the disability originate before age 18, that it can be expected to continue indefinitely, and that it constitute a substantial handicap as newly and more explicitly defined in S. 462. We understand that under this definition those services which are provided under other programs, such as education, mental health, or vocational rehabilitation services, are not provided under this program. This approach will limit the program to those now being served in order to to maintain the sharp focus of this program on its legitimate target group and will prevent the program's resources from being unduly diffused over a wide range of individuals as a result of an otherwise vague definition.

University Affiliated Facilities

Our bill would not include, as would S. 462, an authorization for grants for renovation and construction of university-affiliated facilities. These grants were needed in the original Act to foster the initial construction of these facilities. However, since many such facilities now exist, this Federal assistance is no longer needed. Moreover, this authorization has not been funded for the last few years, and we therefore see no justification for continuing it. Instead, we recommend that funds available for university-affiliated facilities be used for demonstration and training grants for such facilities.

The authority for grants to university-affiliated facilities in the Administration's bill would be similar to that contained in current law, except that the emphasis of such projects would be focused on interdisciplinary training programs and other demonstration training projects and would not include the administration of demonstration facilities.

We disagree with the contention of this Committee, as expressed in the Committee report on H.R. 14215 during the last Congress, that the UAF program was created primarily to provide services to the developmentally disabled. We believe that the primary goal of this program has been, and should continue to be, to provide training for professionals who work with developmentally disabled persons. We believe that the Satellite Center program that would be established by S. 462 is not in line with this basic training objective of the UAFs.

Declining Federal Match

We propose in our bill that the Federal matching share for State grants under the Developmental Disabilities program be gradually reduced from seventy percent in 1975 to sixty percent in 1976 and fifty percent in 1977. We believe it is appropriate for State and local governments to assume an increasingly greater degree of responsibility for service programs that affect their citizens, and that they should progressively increase their share of support for these programs.

National and State Advisory Councils

The provisions in S. 1194 pertaining to the National Council on Services and Facilities for the Developmentally Disabled and the State planning and advisory councils would embody current law rather than the expanded provisions contained in S. 462. We believe that such expanded functions are inappropriately assigned to such councils because they vest operational authority in the councils which would impede the effective administration of these programs by the responsible Federal and State officials.

Federal Approval of Construction Projects

The Administration's bill would eliminate the requirement for Federal approval of construction projects under the State grant program. The deletion of this requirement is in accord with our objective of returning responsibility to State and local governments whenever it is appropriate to do so.

Time Limitation for Regulations Promulgation

S. 462 would require the Secretary to promulgate final regulations implementing Title I within 90 days of the bill's enactment. Because of the need to consult with interested parties and to issue a notice of proposed rulemaking before those regulations can be put into effect, we regard such a time limitation as unrealistically short and as a serious impediment to the promulgation of effective regulations. Moreover, this provision represents another potential limitation on the flexibility of the Department to manage its programs. Therefore, we have included no such provision in our bill.

Evaluation of Services

Our bill would require the Secretary to develop not later than February 1, 1977, a design for a comprehensive evaluation system to be implemented by the States in phases. Each State receiving funds under this Act would be required to implement the first phase of that system not later than October 1, 1977. We believe that such an approach to evaluation is more realistic and effective than the unworkable requirement in Section 121 of S. 462 for the development by the Secretary within eighteen months of an evaluation system and plan for implementation thereof which would be a model for State evaluation systems for all services delivered to persons with developmental disabilities.

Special Projects Authority

Our bill would provide a special projects authority which would include authority for the Secretary to fund projects of special national significance. The ten per cent set-aside for this purpose in the State grant portion of the Act, which exists in present law and which would be continued under S. 462, would therefore be deleted.

Consonant with the aim of inducing greater State and local involvement, the Administration bill proposes terminating Federal support for individual special projects after three years of initial assistance. This provision will give States and localities greater incentives to scrutinize these programs and evaluate their effectiveness.

In addition, our bill would provide that projects funded out of this special project grant authority could not receive funding under Section 304 of the Rehabilitation Act of 1973 or Section 303(a)(2) of the Public Health Service Act. These are the two authorities under which service projects are presently funded. Since we are proposing to create a new project grant authority for the developmentally disabled to replace these present authorities, we feel that these authorities should not continue as a source of funding for such projects. S. 462 would eliminate Section 304 of the Rehabilitation Act as a funding source for these projects, but not Section 303 of the Public Health Service Act.

Authorizations

Lastly, our bill would provide for authorizations of appropriations which would correspond to the amounts set forth for these programs in the President's budget for fiscal year 1976. Thus, our bill would authorize the appropriation of a total of $160.9 million through 1977. Of this amount, $12.5 million for special projects has already been appropriated for 1975 in P.L. 93-517, the Labor-HEW appropriations bill. The Senate bill, on the other hand, extends the program through 1979 with total authorizations of $710.7 million. We believe that, in light of the many demands on the Federal budget and the severe Federal deficits which we are facing in the upcoming years, the authorizations in S. 462 are far too high.

Quality Assurance

Now, Mr. Chairman, I would like to turn to the very complex subject of quality assurance in facilities providing care for developmentally disabled persons. The point I would like to emphasize once again for the Subcommittee is that our Department is presently undertaking a far-reaching effort to upgrade the quality of care provided to developmentally disabled persons in medical or rehabilitative residential institutions. On January 17, 1974, we published regulations establishing extensive standards for Intermediate Care Facilities for the Mentally Retarded (ICF-MR's), and we are now engaged in the major task of implementing them. These standards, which we believe largely implement the same objectives as Title II of the Senate bill, relate to habilitative services, medical care, fire safety, physical environment and sanitation. They aim at assuring that residents of ICF-MR's receive an array of services keyed to their individual needs so that they may reach their maximum potential. These regulations will have a substantial impact on the well-being of the many thousands of developmentally disabled persons who reside in such facilities.

The ICF-MR regulations, which are based on the recommendations of the Accreditation Council for Facilities for the Mentally Retarded of the Joint Commission on Accreditation of Hospitals, were issued under Title XIX of the Social Security Act. Consequently, they apply to all ICF-MR's certified for Medicaid reimbursement. Implementation of the standards must be completed by March 1977. This phase-in period will allow many facilities to complete the expensive and time-consuming renovations which the regulations will necessitate. Each intermediate care facility approved to participate in Medicaid must, no later than March 1975, have a detailed plan for meeting the requirements by 1977. If it does not progress in accordance with that plan, it will be barred from continued participation in the Medicaid program.

Our experience in developing and implementing these regulations indicates that the level of detail of the standards represent the limit that realistically can be expected of the network of facilities serving the developmentally disabled. While we recognize that the ICF-MR standards alone will not succeed in raising the quality of care in all our institutions serving the developmentally disabled, we believe that to go beyond these standards in the way that Title II of S. 462 proposes to do would be to make unrealistic demands on the thousands of agencies and facilities involved. Such demands could result in a major disruption in the delivery of services to the developmentally disabled and create considerable confusion and uncertainty for, and in many cases termination of services provided by, individual facilities and agencies.

Last year, we prepared a rather detailed analysis of Title II of the Senate bill, which is attached to the letter transmitting to the Congress our new bill to extend the Developmental Disabilities Act. A copy of that letter, with the attached paper, has been forwarded to each member of the Subcommittee. While our objections to that Title are described in detail in the paper, I would like to cite just a few examples of the disastrous results which would ensue from enactment of that legislation.

1. Section 204 authorizes the Secretary to make grants to assist States in bringing publicly operated and Federally assisted residential or community facilities and agencies into compliance with the Title II standards. While the number of facilities affected by Title II is unknown, for the purposes of preparing cost estimates we have estimated that at least 6,000 facilities are involved. A

conservative estimate of the amount needed by each residential institution over 5 years to bring itself into compliance with the Title II standards would be $1 million. Thus, at a minimum the cost of bringing each facility into compliance with these standards would be $6 billion. This total would be reduced to approximately $1.250 billion if only residential facilities which provide medical services received the financial assistance; however, this lower figure does not take into account thousands of facilities providing personal care and thousands of community service agencies, all of which would be affected by Title II.

2. Section 205 of S. 462 would permit "Federal assistance payments authorized under Federal law" to "publicly operated or assisted facilities for the developmentally disabled only if" the facility provides evidence that such payments have not resulted in nor will result in any decrease in per capita State and local expenditures for services for the developmentally disabled which would otherwise be available to the facility. While we do not object to the concept of maintenance of effort requirements, we believe that perpetual maintenance of effort obligations are undesirable. Moreover, we object to this particular provision because we feel it is inequitable to hold an individual facility responsible for assuring that State payments to the facility do not decrease. In addition, it is possible that this section would not accomplish its desired effect since there is no sanction to be applied against States who fail to maintain total current expenditures for the developmentally disabled.

3. Section 206 of S. 462 would authorize the withholding of all Federal payments, whether direct or indirect, to any program of community care or residential facility for individuals with developmental disabilities unless it meets the standards established by Title II within five years. Our principal concern with this provision is that it could result in a major disruption in the delivery of services to the developmentally disabled and to others in facilities which receive Federal reimbursement for services rendered. This provision would create considerable confusion and uncertainty for both States and individual facilities and agencies which are currently in the midst of planning for and implementing the existing Federal ICF standards. In addition, because Section 206 would apply to facilities receiving Medicare and Medicaid reimbursement, it could create hardships for the nondevelopmentally disabled populations receiving services in such facilities, since it could result in a facility's loss of Medicare or Medicaid funds for all of its patients. Lastly, this provision, since it would apply to so many different facilities and so many sources of Federal funds, would create an overwhelming administrative burden, since residential and community facilities and programs receive Federal funds from a variety of State and local, as well as Federal, agencies. Effective enforcement of the withholding of Federal funds, particularly enforcement with respect to funds paid indirectly as a result of revenue sharing, would require a massive monitoring and tracking effort, involving a great increase in Federal regional manpower.

4. Section 211 of S. 462 requires individual written habilitation plans to be developed and modified at "frequent" intervals on behalf of each developmentally disabled person who is residing in a residential facility, community facility, and agency to which the Title II standards apply. We estimate that the cost for an initial evaluation of an individual would be $400, based on the services of a 4-man basic team working one half of a day. Quarterly evaluations would be an estimated $100 each. The first-year cost for the habilitation plan would therefore be an estimated $700 per person, or a total of $5.6 billion, based on an estimated population of 8 to 8.5 million persons. This estimate of the affected population is considered conservative; other estimates have placed the target population at 20 million.

Not only would the cost of Section 211 be prohibitive, but it would require measurement in areas where assessment is difficult to make, such as affective and cognitive development. There are only a few personnel trained well enough to make the sort of assessments required under this section.

5. Section 212 would require that each developmentally disabled person served by a facility or agency be assigned a program coordinator responsible for implementation of the person's individual written habilitation plan. For an estimated population of 8 million person[illegible] 1.3 million highly trained health personnel would have to be available to serve as program coordinators. Moreover, as I indicated earlier, these personnel would have to be exceptionally well trained in order to perform the functions required by Title II. This number of highly trained personnel is simply not available.

Mr. Chairman, I think you can see that the resources in terms of manpower and money that would be needed to enable the many facilities and agencies affected by Title II to comply with the requirement of that Title are not available. I greatly fear that the result of placing such clearly unrealistic demands on these facilities would only result in their refusal to provide any care at all for developmentally disabled persons. Such a result would, in my opinion, be clearly undesirable and counter to the objectives that both the Congress and the Administration share - improved care for these persons.

We believe that we should be looking to the next step to be taken beyond the existing ICF quality assurance program. It is our judgment that the next initiative in quality assurance needs to focus on the residents themselves, to ensure that they are receiving and responding to effective programs of care that are helping them to develop and to reach their potential as fully as possible We refer to this approach as the outcome approach of quality assurance, wherein we seek to measure a facility's performance by the results it produces with its residents. While we have long been committed to such an "outcome" approach - indeed, this idea received considerable discussion in the Department at the time the ICF regulations were being developed -- we have lacked the technological ability to implement it. However, recent developments in the developmental disabilities field -- some of which occurred in projects sponsored by HEW -- hold promise that we can move in this direction. Unfortunately, technology will not allow us to adopt national outcome standards such as those proposed by Part B of Title II of S. 462, but an outcome approach does constitute the next necessary step in our efforts to raise the standard of care for the developmentally disabled. We believe we should have authority to move in this direction as the approach is validated. For the reasons stated above, we strongly oppose the enactment of S. 462 and urge instead the prompt enactment of the Administration's bill as an effective instrument for meeting the needs of the developmentally disabled population.

This concludes my statement, Mr. Chairman. My colleagues and I will be pleased to answer any questions you and your Subcommittee members may have.

Department of HEW Responses to Questions Posed to Assistant Secretary Stephen Kurzman by Various Members of the Subcommittee on the Handicapped

Senator Stafford

Q: (From page 40 of Transcript of Proceedings of March 18 hearing).

You say that "We believe that such expanded functions are inappropriately assigned to such councils because they vest operational authority in the councils which would impede the effective administration of these programs by the responsible Federal and State officials." This is under the subject, "National and State Advisory Councils." Could you detail for us the functions incorporated in S. 462 which apply especially on a State level?

A: In general, we object to some of the provisions in S. 462 outlining the functions of the State Planning Councils because we believe that they assign to the Councils a scope of authority that is excessively broad. These provisions would, we believe, substantially diffuse the operational authority of the agencies in the States charged with administrering the Developmental Disabilities program as well as those administering other programs.

For example, clause 115(b)(3) would require the State Planning Council to establish priorities for the distribution of funds for programs for persons with developmental disabilities within each State. The scope of this provision is unclear, for it could be interpreted to give the State Planning Council the authority to establish spending priorities for all spending programs affecting the developmentally disabled (including Medicaid, Maternal and Child Health, education, social services, etc.). Clearly, such broad authority would be obstructive and undesirable.

Clause 115(b)(4) would require that the State Planning Councils review and comment on all State plans which relate to programs affecting persons with developmental disabilities. Again, this provision would diffuse the operational authority of some of the major State agencies with the responsibility for administering such programs as education and Medicaid. Moreover, the Councils meet too infrequently and often lack the expertise to provide the extensive review and comment required for all such State plans. Finally, we believe that this requirement is unnecessary since the make-up of the Councils as specified in S. 462 is adequate in itself to insure proper coordination among programs.

Subsection 115(e) would require the State Planning Council to approve the design for implementation of the State plan. This provision would clearly grant the State Council authority over the operation of the State agency. Such an extension of the Council's authority would be inappropriate and undesirable.

Senator Williams: Question 1

Q: What do you believe the Federal role is in ensuring that the rights of individuals in residential or community facilities are protected?

A: In responding to this question we will limit ourselves to the role of the Department of Health, Education and Welfare. As you know, a multiplicity of Federal agencies are involved in the protection of the rights of individuals in these facilities--including the Departments of Justice, Labor, Housing and Urban Development, Defense, and Transportation, among others. The role of this Department in ensuring that the rights of individuals in residential or community facilities are protected includes the following:

1. The establishment through regulations of uniform standards governing residential and community facilities, and the enforcement of such standards through proper monitoring mechanisms. The Department has established standards through the ICF regulations, the "Patient Bill of Rights" regulations for skilled nursing facilities and intermediate care facilities, Federal requirements relating to the removal of architectural and transportation barriers, and regulations establishing the protection of human subjects.

The effort of establishing and enforcing standards also involves such activities as assisting in the training of surveyors, and assisting in the education of providers, professionals in the field, consumers, consumer advocates, and the general public regarding Federal requirements.

2. Assisting in the education of consumers, consumer representatives, providers, professionals in the field, and the general public to recognize the rights of the developmentally disabled and develop effective means for protecting those rights. This is done through a variety of methods including development of materials, technical assistance activities, meetings, and training.

3. Assisting in the development of effective mechanisms for protecting individual rights such as the funding of projects relating to client advocacy.

4. Working with interested groups and the public to identify problems relating to protecting the rights of the developmentally disabled, and to develop solutions to those problems. Providing both technical and financial assistance in joint efforts between states, knowledgeable citizens and groups, and the Federal government.

5. Promoting recognition of the rights of the developmentally disabled.

Senator Williams: Question 1 (cont.)

6. Providing technical assistance to public and private agencies and organizations ensuring that rights of individuals in residential and community facilities are protected--e.g. Department of Justice, state enforcement agencies, consumer advocates.

7. Evaluating, studying and researching problems relating to protection of individual rights in residential or community facilities and developing solutions to those problems.

Senator Williams: Question 2

Q: You say that the Administration has reviewed very carefully what needs to be done, and that the standards of care should be improved. What action steps would you take or do you plan to take to improve that care?

A: We are engaged in a variety of activities related to improving the standard of care. As you know, survey and certification of intermediate care facilities under the first phase of the revised ICF requirements is occurring this year. This will be followed by an enforcement effort to assure that facilities for the mentally retarded or persons with related conditions (ICF-MR's) are progressing as the regulations require toward compliance with the second phase of the ICF-MR requirements, which must occur by March 1977. The survey and certification activities are being carried out by the State survey and Medicaid agencies. There will be careful Federal monitoring of the States' activities in this area through the Regional Director's offices in each region.

During the survey and certification process, we will also be providing technical assistance to help assure that the Federal standards are understood and the available resources are used in the most effective way in order for the Federal standards to be met. Additionally, we have been and will continue to evaluate gaps between the JCAH and ICF standards and the level of actual functioning, not only in facilities participating in the Medicaid program but in a variety of other residential facilities. We also have been and will continue to ascertain the gaps between the JCAH standards for community facilities and agencies and actual functioning of agencies in that category. This evaluative activity is occurring under a contract with the JCAH. As a consequence of these and other research and demonstration and contract activities, and in light of other experience we will be gaining with the new ICF regulations, we will be reviewing the ICF requirements and modifying them as appropriate. We will also be considering the experience gained under them in determining what steps should be taken with respect to other services provided to the developmentally disabled.

We are also engaged in an ongoing assessment of the services for the developmentally disabled on a State-wide, as well as on a nation-wide, basis. This assessment is being carried out by the DD State Councils, our National Advisory Council, and Department staff in coordination with other Federal departments, State agencies and public and private organizations. Included in this assessment process are the identification of existing services, gaps in services, areas in which quality should be improved, and effective service programs which can be used as models; the coordination of existing resources to develop services to fill gaps identified and to improve the quality of services (this process includes the identification of available Federal and other resources, the development of Federal "blueprints" for accessing services, and assuring that resources which are available are in fact utilized); and the development of proposals for new projects.

Senator Williams: Question 2 (cont.)

We are engaged in enforcement of a variety of Federal requirements outside of the ICF area which affect the standard of care given to the developmentally disabled--among these the Federal requirements relating to architectural and transportation barriers and the protection of human subjects in research.

We are funding a variety of research and demonstration projects and contracts aimed at the improvement of existing standards. For example, we are funding projects which promise to lead to the development of more effective means of ascertaining whether good quality care is being given (these are performance evaluation approaches which are discussed at greater length in our response to question 5.) In addition, we are identifying model programs and funding client advocacy projects. From the results we obtain from these projects and contracts we will be able to determine what additional information we need in order to improve the standard of care and to monitor the standard of care more effectively. We will also derive information which will enable us to modify existing requirements to make them more effective. We are also working with the Department of Justice to assure that the right to treatment of the developmentally disabled is protected.

Out of an amalgam of these activities we are, in coordination with others, creating an action plan for addressing the problems of the developmentally disabled which builds on experience gained under our new requirements, research and demonstration efforts, and the experience of others to improve our present requirements and to develop methods for assessing the standard of care provided to the developmentally disabled on a comprehensive basis. We deal at some length in our response to question 5 with the development of a comprehensive evaluative process and how it would intermesh with present and future requirements relating to the standard of care.

Senator Williams: Question 3

Q: Well, now you mention some 1,250 residential institutions that must meet Medicaid regulations. Are these all institutions for the developmentally disabled? What proportion are? What proportion are not covered by these regulations?

What are these 6,000 institutions that you mention at the end of your testimony? Are these all covered by the Medicaid regulations?

A: The reference in the Department's testimony to the 1,250 residential medical facilities funded under the Medicaid program represents our best estimate at this time of the number of such facilities which serve the mentally retarded.

At this time the Department does not have a precise estimate of the number of facilities serving developmentally disabled persons and participating in the Medicaid program. This data will not be available until the survey and certification process under the initial phase of the ICF regulations has been completed. As you know, the surveys of all residential facilities which applied to be surveyed as potential ICFs had to be completed by March 18. As of about March 12, 6,173 ICFs had been surveyed and certified for participation in the Medicaid program. As of the same date there were 3,012 other facilities for which the survey and certification process had not been completed. These facilities are operating under special 60-day extensions while the survey and certification process is being completed. These extensions, which can be granted only under certain conditions specified in the regulations, cannot be granted where the health and safety of the patients would be jeopardized. Thus, the remaining certifications will not be completed for about another month, and we will not know exactly how many ICF-MR's will be participating in the Medicaid program until that time. Only after further analysis of the data gathered during the initial survey and certification process will we have a more precise idea as to how many of the ICFs participating in the Medicaid program serve the developmentally disabled in whole or in part.

In our testimony we estimated that there are at least 6,000 publicly operated and Federally assisted residential or community facilities and agencies affected by the Title II standards. Although this estimate was rough, we believe it was a conservative one. Under a grant from this Department (entitled "Private Residential Care for the Mentally Retarded") the National Association of Private Residential Facilities for the Mentally Retarded has identified 10,000 of an anticipated 20,000 foster home-family care facilities and nursing homes providing residential services to the mentally retarded. This figure does not include public facilities and community agencies. Thus, we feel that our estimate of 6,000 publicly operated and Federally assisted residential or community facilities and agencies was probably low.

Senator Williams: Question 4

Q: What is the compliance review mechanism you have working for Medicaid? How many individuals in the regional and the headquarters office?

A: In order for a skilled nursing facility or an intermedicate care facility to be reimbursed for the services it provides to eligible Medicare and Medicaid beneficiaries, it must be determined that it meets appropriate Federal regulations concerning health and safety. This determination is accomplished through the survey and certification process The survey and certification process is initiated with the survey of a facility. A survey is performed at least annually for long-term facilities (including ICF's). The survey is conducted in two parts, health and fire safety. The health survey is conducted by a surveyor or team of surveyors employed by the State survey agency. The survey agency is located within the State Health Department and performs the survey function under agreement with the Department of Health, Education, and Welfare. The fire safety survey is generally conducted by the Office of the State Fire Marshall under agreement with the State survey agency.

Following the completion of the survey and necessary documentation of findings, the survey agency certifies to the appropriate authority (DHEW for Medicare, the State Medicaid Agency for Medicaid) that the facility does or does not meet Federal regulations. If the survey agency's certification is positive, the authority enters into a provider agreement with the facility to reimburse for services provided to eligible beneficiaries. The provider agreement is reviewed at least annually as part of the annual survey.

The Department also performs a limited number of direct Federal surveys. These surveys are performed by Federal employees and are done to evaluate the effectiveness of State survey agency performancy.

There are 177 Regional personnel involved in the survey and certification process. These people are located in the Regional Offices of Long-Term Care Standards Enforcement. For FY 1976, the Department has requested an additional 126 positions to strengthen the regional survey and certification activity. There are approximately 35 personnel in HEW Headquarters agencies involved in survey and certification.

Senator Williams: Question 5

Q: Now, let's talk about the evaluation system a bit. What we have in mind is putting in place an evaluation system which works on the basis of the progress or the development of the individual receiving care. Right now, there is a major project ongoing in this area, funded by the Department; there are upwards of 10 scales which propose to measure individual behavior; there are at least 8 or 9 states which are utilizing some form of this scale to measure the outcomes. It seems to me to make all the sense in the world to have the Federal Government invest in this and lead the way so that we do not have each State making its own mistakes, and all of them ending up with systems which cannot communicate with each other. It also seems to me that this break-through in outcomes measurement could be one of the most significant changes in care and evaluation in years, and that no matter what the problems, we ought to invest in it and start trying to make some decisions in this area. What you are saying is that you want the flexibility. Well, I want flexibility too, but I want this done. Otherwise, we would be talking at each other across this podium three or four years from now and you will be telling me the same thing.

A: We urge congressional enactment of the evaluation section of S. 1194. Not only will this section help to improve our capability to evaluate the status of the developmentally disabled but in effectiveness of our ability to assure the quality of services in facilities and agencies providing care and services for developmentally disabled persons.

As stated by Assistant Secretary Kurzman before the Subcommittee on March 18, 1975, ... "We have long been committed to such an 'outcome' approach ... recent developments ... hold promise that we can move in this direction. Unfortunately, technology will not allow us to adopt national outcome standards such as those proposed by Part B of Title II of S. 462, but an outcome approach does constitute the next necessary step in our efforts to raise the standard of care for the developmentally disabled."

We see as a basic strategy for improving quality assurance to keep the ICF Standards as the limit of what can reasonably be done with input and process standards and in an evolutionary fashion over time adding to and replacing these standards with outcome standards as fast as the approach is validated.

The first step consists of establishing the evaluation system specified in our legislation. We think we can and should start to develop this system. Under the evaluation section our plan is to develop measures of developmental progress. This would provide a means to validate the outcome measure approach to quality assurance and, in the long run, will allow us to extend ICF and other

Senator Williams: Question 5 (cont.)

relevant regulations in this direction. As a part of the evaluation effort we would develop performance based criteria for assessing the quality of care in residential facilities. We would use our experience gained from various experimental programs funded by the Department and the knowledge we will be gaining through enforcement of the new ICF regulations.

One possible approach that we plan to consider would directly build upon and preserve the existing Title XIX ICF-MR Standards but additionally would require every ICF-MR institution certified for reimbursement to establish an internal quality assurance system based upon "outcomes." The institution would be required to set institutionwide measureable outcome goals for the various groups of residents it serves, to objectively measure progress, and to institute plans of institutionwide improvement in the event goals are not met. Further, institutions would be required to report results to us, giving us a much better picture of just how well off the developmentally disabled are across the nation. These systems would be established in accordance with Federal standards based on the evaluation system we propose to develop. The ICF-MR Standards would consequently be revised over time, thus stimulating and requiring gradual advancement in the adoption of outcome oriented standards and the gradual movement away from input and process standards. (See McClure, 1972 and Williamson, Johns Hopkins for a more detailed description of this approach.)

Of course, the same approach would be considered for other funding authorities such as services and facilities funded under the DD Act, etc.

Note that this is only one possible approach and before this or any approach is adopted, we need to be sure it would represent an effective step forward rather than merely resulting in paper compliance.

It is important to note that while we feel that a new forward step is desirable, it is clearly imperative that it be implemented only at such a time and in such a way that it will not interfere with the tasks the states face in implementing the existing ICF-MR regulations. Thus, the evaluation section becomes a logical and appropriate means for the aggressive development and testing of this approach to quality assurance so that at the appropriate time results can be applied to the ICF-MR and other regulations thus upgrading our quality assurance effort.

It should be noted that in our exploration of the technical feasibility of establishing an evaluation system we have worked very closely with the project directors of ongoing HEW funded efforts. Specifically, we have held lengthy discussions with Dr. Richard Eyman, Project Director of the California Clients Tracking System which now involves 18 states. Our comments are heavily based upon these inputs. The California System "tracks"

Senator Williams: Question 5 (cont.)

client status using the AAMD Adaptive Behavior Scale as a measure of developmental progress of individuals. The system has not yet developed operational means of evaluating service impact. Thus, although some initial research has been started in this area it is in the very early experimental stages. In short, the California System does not currently represent an operational service evaluation system which can be directly transferred for quality assurance purposes.

We agree with your objective of putting in place an evaluation system which works on the basis of developmental progress. The Administration's bill S. 1194 proposes to do exactly this. In fact, our language was developed after discussions with Senate staff and we seek to accomplish the same objectives through more feasible means. The rationale for the differences between the language in the Administration bill, S. 1194, and the Senate bill, S. 462, was presented to Senate staff last fall and is attached at the end of this answer.

In summary, the major differences between the evaluation language of these two bills are:

(a) The Administration bill allows approximately 24 months for system design in contrast to approximately eighteen in S. 462. We feel this time will be needed to accomplish this very ambitious technical effort.

(b) The Administration bill calls for a time phased implementation plan, whereas S. 462 calls for a comprehensive one-step system implementation. We feel that states should not stop with the implementation of a first step, but rather should build over time on an initial system once established thus allowing for ever-increasing evaluation effectiveness as new technology becomes available. Also, we recognize that states are starting from different levels of sophistication. Thus, a phased implementation plan recognizing state differences seems not only prudent but necessary.

(c) The Administration bill is more general in its specification of the content of the evaluation system than is S. 462. This raises two inter-related issues: 1) the Administration's accountability to Congress, and 2) the technical uncertainty related to the design of the evaluation system.

Both the Administration bill (S. 1194) and S. 462 call for a report to Congress prior to system implementation. S. 1194 carefully specifies that the report must contain both the comprehensive evaluation system design and the implementation plan. Cost estimates are also required. The intent of this provision is to allow Congress

Senator Williams: Question 5 (cont.)

to fully review the products developed and to determine if they satisfy the Congressional intent. Given the technical uncertainties it seems far more prudent to make final decisions on a design specified following in-depth feasibility analysis. It seems arbitrary and unwise to legislate specific design characteristics of the evaluation system at this time given the complexity of a comprehensive evaluation system and knowledge limitations.

However, based upon our preliminary technical review and discussions with Senate staff we furnished to the Congress last fall our best "crystal ball" estimate of how an evaluation system might be designed if our preliminary judgments prove to be technically feasible. This is presented on page 3 of the attachment. We officially submitted this rationale behind our proposal for inclusion in the Committee report.

Again, the reason flexibility in the specification of the system design is required in the legislation is that various technical questions remain unanswered at this time. The key technical issues and the state of the art are summarized in the attachment (Paragraph 4, page 1). We have talked to many technical "experts" and found there to be agreement on some points and wide disagreement on others. For example:

(a) There is general agreement that there are a number of scales in use which measure some important components of developmental progress.

(b) There is agreement that none of these scales should be Federally mandated for national use at this time.

(c) There is not a concensus that a single scale should ever be mandated for national use. Instead some recommend that Federal standards which scales must meet be established along with Federal designation of exemplary scales. This approach could allow for continued technical improvement, State flexibility in relation to particular needs, and sufficient standardization through Federal guidelines to allow for data comparison. Clearly this is a complex design issue.

(d) There is a concensus that it is now, and will remain for some time, technically impossible to assess the adequacy of all education and other services or assistance to persons with developmental disabilities under laws administered by the Secretary as specified in S. 462, Sec. 121 (b).

(e) There is a concensus that the following provisions of S. 462, Sec. 121, are also impossible now and will probably remain so in the immediate future:

    (1) "evaluate the effects of services on the lives of consumers ..."

Senator Williams: Question 5 (cont.)

(2) "evaluate the overall impact of State and local programs for the developmentally disabled."

Unfortunately, very little is known about the cause and effect relationship between any HEW services and the lives of service recipients either individually or in aggregate.

While these goals cannot all be achieved in the next 36 months, technical progress offers the promise that we can move toward them over time and that there is much to be gained by doing what is technically feasible within the scope of this legislation and further to create a system which will allow States and, in fact, require them to continue to build upon an initial system as rapidly as technology and resources allow.

Senator Williams: Question 5 (cont.)

ATTACHMENT

RATIONALE FOR AMENDMENTS TO THE SENATE-PASSED VERSION OF H.R. 14215 EVALUATION OF SERVICES, PROGRAMS, AND FACILITIES AFFECTING INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES.

1. Sec 207 is redundant with Sec. 121. Thus, both studies should be merged into a single modified Section 121 as described in (3) below.

2. The intent of Section 210 seems to be to use objective measures of the developmental progress of persons with developmental disabilities as a basis for establishing performance criteria for residential and community facilities and agencies and further to require compliance of facilities and agencies with such criteria. The development of criteria would be incorporated into a single evaluation system under Sec. 121 as proposed by the Department (see (3) below); consequently, Sec. 210 is redundant.

   The state-of-the-art makes it imprudent to mandate the use of such measures as performance criteria in advance of their development, although the eventual use of such measures in this way seems to offer promise. Thus, it seems entirely consistent with the intent of the Senate to incorporate Section 210 into our proposal for a revised Sec. 121 which would require the development of measures and their time phased orderly implementation by states as technical developments and implementation feasibility allow.

   The following comments on the state-of-the-art bear on the imprudence of mandating, at this time, the use in relation to compliance of this type of performance measure. The technical development of such measures can usefully be thought of as consisting of three successive stages: (1) design of objective measures of developmental progress of individuals with developmental disabilities, (2) determination of relationships between developmental progress by individuals and services and living environments, and (3) development of performance criteria which reflect the product of (2) above and which are effective and practical to use as compliance levels for operating residential and community facilities and agencies.

   A number of measurement scales of varying merits exist and are in limited use. Only one project (being undertaken by the Kansas UAP and still in its pre-operational stage) is known to exist for Stage 2, although there may be others. Thus, Stage 2 appears to be beyond the state-of-the-art at present. Stage 3 can be developed only when Stages 1 and 2 are complete or nearly so.

Senator Williams: Question 5 (cont.)

3. We support and accept the basic concepts implied in Section 121 of the bill; specifically (1) the value of federal leadership in the development of an overall evaluation system concept, relevant methodologies with implementation guidelines, and federally required standards; (2) the development of specific criteria designed to provide objective measurement of the developmental progress of persons with developmental disabilities, and (3) the potential utility of including in an evaluation system some of the recent developments under DHEW sponsorship related to individualized data systems. It will be especially useful to establish an initial coordinated federal-state effort and system which can be built upon over time as we learn more.

While in agreement with the intent, we are concerned that the comprehensive evaluation of social programs is an extremely ambitious undertaking beyond our present capabilities. Thus, it is necessary that evaluation methods be carefully assessed prior to federal endorsement. Further, it is important that the real merits of the evaluation system along with its potential for future growth not be compromised by overambitious requirements for initial state implementation.

Consequently, our proposed amendments call for a time-phased implementation plan. It is intended that the Secretary develop within approximately 24 months guidelines and alternative methods for a fully comprehensive system so as to assist all States in meeting this goal at the earliest possible date. (Approximately 36 months after enactment at the latest.) However, recognizing that some states have little or no foundation on which to build, a "minimal" system only is required for implementation as a first step. The "minimal" system is required to be directly compatible with expansion to a comprehensive system. The requirement placed on the Secretary to develop the design of a fully comprehensive system in addition to specifying a minimal system and implementation plan is intended to a) advance the state-of-the-art as aggressively as possible, b) allow the more advanced States to proceed beyond the minimal system, and c) provide an informed and technically sound basis for further legislation in the future.

Given the complexity of a comprehensive evaluation system and knowledge limitation, it seems arbitrary and unwise to legislate specific design characteristics of the evaluation system at this time. These would best be finally determined during the design phase which would include in depth feasibility analyses and would be delivered to Congress in the report due no later than February 1, 1977.

Senator Williams: Question 5 (cont.)

However, the following features are suggestive of our current best thinking as to how such a system might be designed:

(a) The comprehensive evaluation system required by subsection (a) might, if feasible, be designed to:

(1) provide objective measures of the developmental progress of persons with developmental disabilities using data obtained from individual habilitation plans as required under section 211 of this Act (where applicable) or other comparable individual data;

(2) provide objective measures of the value of living environments and associated services in promoting developmental progress of persons with developmental disabilities which could be used as performance criteria applicable to residential and community facilities and agencies (Note that this time is directly responsive to Section 210 which would be replaced by the proposed language);

(3) provide general designs of alternative Statewide data systems which could record (A) the developmental progress of developmentally disabled individuals, (B) objectives and service plans stated in individuals' habilitation plans, and (C) all services or assistance received by such individuals under programs administered by the Secretary;

(4) provide uniform evaluative criteria, standardized definitions, and methodologies which could allow for aggregation and use of data relating to such developmental progress for Statewide and nationwide evaluations of service effectiveness, with due regard for (A) the protection of the rights of privacy of, and the confidentiality of data relating to, developmentally disabled individuals and (B) variances in service from State to State;

(5) provide statistical and other evaluative methods which could, using data in the systems, support directly (A) evaluations of the effectiveness and efficiency of alternative services provided to developmentally disabled individuals and (B) planning activities related to developmentally disabled individuals, including but not limited to the activities of State Developmental Disability Councils and Agencies and the preparation of State plans required for Federally-supported programs administered by the Secretary which provide assistance to individuals with developmental disabilities.

Senator Williams: Question 5 (cont.)

(6) provide for data collection and sampling methods which would help evaluate the extent to which indiviuals with developmental disabilities in communities are not being reached by service programs, thus supporting an evaluation of the effectiveness of the DD program in planning for and achieving gap-filling for individuals with unmet needs. (For example, the feasibility of evaluating unmet service needs of SSI recipients or applicants with developmental disabilities could be examined).

(b) The time-phased implementation plan required by subsection (a) might be designed to--

(1) recognize differences in State size, characteristics and distribution of developmentally disabled individuals, administrative structures, service delivery practices, and relative degree of data and evaluative system development;

(2) specify a minimal system for the evaluation of services to individuals with developmental disabilities which —

(A) is capable of being implemented by all States within the time specified in section 114(b) (18);

(B) is compatible with expansion over a period of time to a comprehensive system;

(C) includes the evaluation of the developmental progress of a significant sample of individuals with developmental disabilities (i) residing in public and private institutions qualifying as intermediate care facilities under title XIX of the Social Security Act, and (ii) in State operated or supported schools providing services to children with developmental disabilities under section 121 of title I of the Elementary and Secondary Education Act of 1965.

(3) provide guidelines and methods which will assist States in the implementation of those comprehensive system features which are beyond the minimal system.

Senator Williams: Question 6

Q: Could I ask where you got the figures on the program coordinator. The figures you are using assumes a 1 to 6 coordinator to patient ratio, and that is preposterous for any kind of care. In California, where a system like this is working, the ratio is in a range from 1:40 to 1:120, or an average of 1:85.

A: The figures we used were based upon our assessment of the kind of ratio which should be employed, given the nature of the duties that would be required of the program coordinator under Section 212 of S. 462. The requirements for Qualified Mental Retardation Professionals established in our ICF regulations, as well as the requirements specified in the case of *Wyatt* v *Stickney* (styled *Wyatt* v *Aderhold* on appeal), specify that persons coordinating the habilitation plan of the developmentally disabled individual must be highly qualified professionals and must be actively involved in the implementation of the habilitation plans. We very much doubt that with a caseload of 1:85 the coordinator would be able to review the plan of care for the individual closely and frequently in order to recognize deficiencies in the program provided to the individual and assist in developing solutions.

Our estimates, then, were based on what we consider to be the minimum ratio necessary to perform adequately the role of program coordinator as defined in S. 462.

Senator Javits

Q: If the definition of "specific learning disability" was altered to make clear that SLD has definite parameters -- such as constituting an inability to keep up with one's peer group, for example -- would inclusion of SLD in the definition of "developmental disability" be more acceptable to the Department?

A: The Department feels that the phrase "not being able to keep up with their peers" is far too broad to define a substantially handicapped developmentally disabled person. Many children "fail to keep up with their peers" for such widely divergent reasons as malnourishment and poor health, poor mental health and emotional reactions to social stress, or lack of positive motivation. Most "failing" children could be classified under such a broad definition of specific learning disability. The definition can be far too easily misconstrued, misused and abused.

The Department perceives the serious problems of the learning disabled as demanding the full attention of the educational system. However, we are of the conviction that these are representative of the problems of the Office of Education in attempting to meet the needs of other educationally handicapped children and youth. These are the generic education services needed by the educational system that can be utilized by students with a variety of types of handicaps in addition to the developmental disabilities as defined in this Act.

Moreover, we do not agree that the problems of the severe learning disordered child persist in a severe form beyond youth and outside of the educational domain. Just as a segment of the mentally retarded, cerebral palsied and epileptic population are not considered developmentally disabled because their handicaps do not seriously impinge on their adjustment to life in the community, the administration regards the adult with a severe learning disorder as being as capable of adjustment as most persons who are only midly affected by mental retardation, cerebral palsy, or epilepsy.

Senator Randolph: Question 1

Q: Mr. Secretary, as you know, most of us in the Senate are acutely aware of the bad state of our economy. The information I have been getting from governors, mayors, and other representatives of our States and local governments does not lead me to believe that this is a very good time to ask the States to assume an increased share of this program. You will recall that this program was initiated because services for handicapped persons have never been given a priority at the State and local levels. When it becomes necessary to cut budgets at those levels, the first items to be cut or eliminated (if they have been included at all) are those relating to the handicapped. This is why the Federal government has initiated this program and others to assist the States in bringing services to the handicapped. Now, Mr. Secretary, with the States having to increase their taxes and cut their budgets in order to survive, do you think it is an appropriate time to reduce the Federal matching share in this program?

A: The administration is sensitive to the financial problems of the States, but finds itself in the position of considering the relative dilemma of the States as compared to Federal deficits. The Federal deficit for FY 1976 is currently estimated to exceed the $53 billion predicted in the President's budget for FY 76. The strategy, then, is one of extending the Federal dollar as much as feasible with minimum compromise of critical programs.

In addition, experience has shown that programs or projects are more apt to continue on a permanent basis if the Federal share is such that the matching share represents a significant, although reasonable, sponsor commitment. When the matching share is significant, projects are funded on a more selective basis. It is not intended, in this statement, that the matching share be prohibitive, but at a level which calls for a project's capability for continuity when Federal funding declines or ends. A State would be more willing to assist a private agency with tax money to meet the matching share if the State were convinced that it would be justified in terms of project excellence and priority to commit tax money to insure continued operation of a project in the event the private sponsor falters financially. The reduced Federal matching share will tend to produce more highly selective programs with broad and relatively dependable bases of support.

Senator Randolph: Question 2

Q: Mr. Secretary, you are no doubt aware of the situation regarding conservation of fuel and energy supplies. I know that there has been a great deal of discussion in other subcommittees of our committee and in appropriations subcommittees regarding the expenditures for travel. As an advocate of the conservation of both energy supplies and dollars, I would be most appreciative if you would provide to the subcommittee detailed information regarding your travel policy. How are priorities determined in the approval of travel, both domestic and foreign? How do you monitor or review expenditures of travel of the recipients of grants, contracts, and other funds? Have you explored the use of the variety of telecommunications as a substitute for travel?

A: Division of Developmental Disabilities

In the Division of Developmental Disabilities, a close review is made of all travel requests to see that they are essential and cannot be handled through correspondence, telephone, or by mail. We have used the Regional Office staff as much as possible in providing technical assistance and have used the resources of the consumer interest groups in communicating with State and local agencies.

Travel by common carrier is preferred. Special justification must be submitted by the traveling employee before approval will be given for travel by privately owned vehicles. Travel by train or bus is preferred for short trips. For local travel, shuttles or bus systems should be used when available.

Normal government travel regulations apply and any use of first class travel must be justified by a separate memorandum signed by the Commissioner of RSA.

Continuing effort must be made to minimize the number of meetings convened (central office and regions) involving travel on the part of any or all participants. All personnel attending such meetings must have a specific task and function to perform.

Meetings of associations and other external groups are by necessity considered to be of secondary importance; attendance involving travel must be drastically reduced or eliminated.

Speaking engagements, except those providing essential information to the public on priority HEW programs are to be eliminated. Acceptance of a speaking engagement must be endorsed and individually reviewed by the Commissioner of RSA or by the Regional Commissioners.

Staff of the Division by March 31, 1974 had spent $14,402 in essential travel. By contrast, at the end of March 1975, the Division had reduced travel expenses to less than $6,700.

Senator Randolph: Question 2 (cont.)

For the MAC members by March 31, 1974 $7,585 had been spent in FY 1974. For FY 1975, only two meetings of the Council are to be held, rather than three as originally scheduled. This will result in a savings of approximately $4,000 in travel.

The Division does not monitor State travel as the authorizations for travel are made at the State level. However, a review of the State travel expenditures in 12 States covering regions V and VIII under the Developmental Disabilities formula grant program showed that travel accounted for $61,000 of Federal funds. This averages out to 4/5 of 1% of the total allotments ($6,700,000) or roughly $5,200 per State per year.

RSA
The attached material outlines the travel policy for RSA.

WHAT IS THE RSA TRAVEL POLICY?

RSA is strictly adhering to the policy established by the Executive Assistant Commissioner, RSA in his memo of Nov. 11, 1974(ATMT. 1.). This policy implements the travel policy announced by the Department on Jan. 25, 1974 (ATMT. 2.) tightening down travel during the current Energy Crisis. These two memos were routed to staff and constitute current RSA travel policy. To implement these travel reduction regulations, travel is approved only by the Commissioner or the Executive Assistant Commissionar, or in their absence by the Assistant Commissioner for Financial Operations or the Budget Officer, RSA.

HOW ARE DOMESTIC PRIORITIES DETERMINED IN THE APPROVAL OF TRAVEL?

All domestic RSA travel is essentially prioritized by a system of requirin Annual Travel Plans from Program Units, a review of this by the Commissio and the overall allocation of travel funds to Program Units. In addition to this overall review, each individual travel request must be fully justi and resubmitted to the Commissioner's Office for approval in accord with established policy and tight budget restrictions.

HOW ARE FOREIGN PRIORITIES DETERMINED ON APPROVAL OF TRAVEL? AND WHAT IS THE FOREIGN TRAVEL POLICY?

Department policy on foreign travel is stated to some extent in Mr. John Ottina's memo of Dec. 30, 1974 (ATTMT. 3).

All RSA foreign travel requests receive 4 reviews to assure necessity:

1. They are closely reviewed by the RSA Executive Director for Research and Development. This includes the justification, costs, purpose, and necessity to the specific needs of the RSA program to which it relates.
2. They are closely reviewed by the Commissioner, RSA for policy considerations.
3. They are reviewed and finally approved within the Office of Human Development by the Assistant Secretary for Human Development
4. They are finally approved in the Department by the Director, Office of International Affairs of the O.S.

To provide an orderly planned review, an annual proposed foreign travel report must be prepared and sent through the above clearance points. This is reviewed at each level on its way up as to needs, priorities, costs, no. of travellers, and foreign relations policy. Upon approval of the Annual Plan, detailed Quarterly Reports are prepared of accomplish travel, including individual reports of travellers.

HOW DO YOU MONITOR OR REVIEW EXPENDITURES OF TRAVEL OF THE RECIPIENTS OF GRANTS, CONTRACTS, AND OTHER FUNDS?

All domestic travel in project grant activities are justified and approved at the time of award of grant. Subsequent rebudgeting within specified government-wide limits established by the OMB is allowable. Each foreign trip must be approved and justified.

HAVE YOU EXPLORED THE USE OF THE VARIETY OF TELECOMMUNICATIONS AS A SUBSTITUTE FOR TRAVEL?

By virtue of the energy crisis, much has been done to increase utilization of telecommunications vs travel. We have established a Mailing Key system for the distribution of policy guides and program instructions, which is directed at the audiences who are most concerned. This has reduced the printing costs. We have available to RSA a Telecommunications Machine which provides exact duplicate copies from Washington to each of our Regional Offices. This is used by staff. In addition, we, of cour make full use of the FTS telephone system to communicate. In order to reduce expenses we have ordered that no long distance calls be made except under the lower cost FTS system.

MORANDUM

DEPARTMENT OF HEALTH, EDUCATION, AND WEL
SOCIAL AND REHABILITATION SERVICE
Rehabilitation Services Administration

TO : RSA Executive Staff

DATE: NOV 11 1974

ATTMT 1

FROM : Executive Assistant Commissioner

SHE

SUBJECT: FY 1975 Travel Restrictions

RSA is currently operating under the Continuing Resolution, which will likely be effective through December.

A severe travel restriction has been imposed on DHEW upon the recommendation of the Senate Committee to hold travel expenditures to the FY 1974 level. As a result SRS has indicated a RSA travel ceiling approximately 11% below our 1974 expenditures. To comply with this restriction, it will be necessary to carefully scrutinize all travel and to recommend only that travel which is most essential. The following criteria are to be observed:

1. Travel to conferences and conventions will be limited to those who are principal speakers.

2. Technical assistance to states and local offices should normally be handled by the appropriate regional office(s).

3. Travel which is not of immediate importance should be deferred until a later date.

Mr. Lavan's memorandum of August 21, 1974 (signed by Mr. Terango) to the Executive Staff regarding the processing and approval of travel orders in FY 1975 remains in effect.

Bill

William S. Hunt, Jr.

page 43 127

MORANDUM

DEPARTMENT OF HEALTH, EDUCATION, AND
SOCIAL AND REHABILITATION SERVICE
Office of the Administrator

SRS Executive Staff

DATE: JAN 25 1974

CC: [illegible]

FROM : Administrator
Social and Rehabilitation Service

SUBJECT: Energy Crisis - Reduction of Official Travel in FY-1974

In the second half of FY-1974, the Secretary has asked DHEW agencies to accomplish a 20% reduction in the consumption of fuel used for official travel over the same period for FY-1973. To meet this objective, the following policies on official travel will be effective immediately:

a. Use of privately-owned vehicle or rental cars is prohibited except when travel by common carrier (train, bus, air) is not available and the trip is urgent.

b. Requests for travel must be reviewed for essentiality in terms of the energy crisis.

c. Travel orders must be approved by Bureau Commissioners, Associate Administrators, and Regional Commissioners, or by persons designated to act for these officials in their absence.

d. Reservations for airline travel should be made sufficiently in advance to enable travel by economy class. Any use of first class travel must be approved in advance by the Associate Administrator for Management.

e. Reduce to a minimum the number of meetings called by SRS involving Regional or Headquarters Staff. Where meetings are determined to be essential, the number of participants involved should be kept to an absolute minimum, i.e., each person attending is to have a specific identifiable function. This pertains not only to meetings held in Washington but meetings held in the field involving Regional and Central Office personnel.

f. Meetings of associations and other external groups are by definition of secondary importance; therefore, attendance involving travel should be drastically curtailed or eliminated.

g. Speaking engagements, except those providing essential information to the public on priority HEW programs (OPS objectives), are to be eliminated. Exceptions to this will be granted strictly on an individual basis.

All travel plans should be reviewed in terms of their impact on the energy problem. Travel by train or bus is the preferred method for short trips; travel by scheduled airline is preferred for long trips. For local travel such as the Parklawn or Woodlawn complexes, shuttles, when available, should be used instead of private cars.

We need the cooperation and support of all employees in this effort, and I expect that the management officials named above will lead the way.

James S. Dwight, Jr.

MORANDUM

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
McCAVITT OFFICE OF THE SECRETARY

O : SEE BELOW

ATTMT 3 DATE: Dec. 30, 1974

make copy for Mr [illegible]

ROM : Assistant Secretary
for Administration and Management

UBJECT: Foreign Travel

Because of the necessity to reduce outlays during the current fiscal year and in view of increasing attention on the Hill to travel performed by Government officials, I have issued reduced foreign travel ceilings to the Department's operating components.

Although we do not issue ceilings to OS staff offices, I would appreciate your cooperation in holding foreign travel to an essential minimum. As you know, each foreign trip performed by an employee of this Department requires the prior approval of the Office of International Affairs Management. If you have any questions concerning this procedure, please give me (57284) or David Hohman (56433) a call.

/s/
John Ottina

ADDRESSEES:

Assistant Secretary, Comptroller
Assistant Secretary for Human Development
Assistant Secretary for Legislation
Assistant Secretary for Planning and Evaluation
Assistant Secretary for Public Affairs
General Counsel
Executive Secretary
Special Assistants to the Secretary

Senator Mondale: Question 1

Q: Will the Federal efforts to develop an evaluation system of developmental disabilities services take into consideration, or in any way duplicate, current efforts now underway within each State?

A: The proposed evaluation system will take into consideration current efforts now underway within each State. In fact, building upon State efforts is fundamental to the evaluation systems development plan proposed by the Administration. In the rationale for our proposal, previously submitted to Congress we stated:

> "The time-phased implementation plan required by subsection (a) might be designed to - ...recognize differences in State size, characteristics and distribution of developmentally disabled individuals, administrative structures, service delivery practices, and relative degree of data and evaluative system development."

Indeed, we see the evaluation system allowing wide latitude for State innovation and preferences within the framework of national standards for key common elements. Further, one of the basic objectives of the initial system design phase, which would be completed by February 1, 1977, is to survey current State efforts so as to have the final system design and the implementation plan reflect State efforts and differences. Also, individual States will be afforded an opportunity to participate in the design of the system.

AFSCME
American Federation of State, County, and Municipal Employees
1625 L Street, N.W., Washington, D.C. 20036
Telephone (202) 452-4800
Telex 89-2376

Jerry Wurf
President

William Lucy
Secretary-Treasurer

Vice Presidents

[illegible] J. Badolato
North Haven, Conn.

Rev. Albert B. [illegible]
St. Peter, Minn.

Jerol L. Brown, Jr.
Sacramento, Cal.

James A. [illegible]
Boston, Mass.

Carl S. [illegible]
Moline, Ill.

James B. Corbett
New York, N.Y.

Ernest B. Crofoot
Baltimore, Md.

Arthur O. [illegible]
Jefferson City, Mo.

Charles L. [illegible]
Toledo, Ohio

[illegible]
Canal Zone

Gerald W. McEntee
Harrisburg, Pa.

Larry [illegible]
Seattle, Wash.

[illegible]
Detroit, Mich.

Robert J. Oberbeck
Madison, Wisc.

Walter L. Oliver
Lansing, Mich.

Joseph R. Rizzo
Buffalo, N.Y.

Earl Stout
Philadelphia, Pa.

Gilbert [illegible]
Denver, Colo.

Lee A. [illegible]
Miami, Fla.

David K. Trask, Jr.
Honolulu, Hawaii

Maynard White
Houston, Texas

Joseph R. Zurlo
New York, N.Y.

March 18, 1975

The Honorable Jennings Randolph, Chairman
Subcommittee on the Handicapped
Committee on Labor and Public Welfare
5121 New Senate Office Building
Washington, D.C. 20510

Dear Mr. Chairman:

On behalf of the American Federation of State, County and Municipal Employees, I am enclosing for the hearing record our statement on S. 462, the Developmentally Disabled Assistance and Bill of Rights Act.

We hope this statement will be helpful to you during your consideration of this crucial legislation. If we can be of any assistance to you, please do not hesitate to contact Nanine Meiklejohn, our Legislative Representative, at: 452-4848.

Sincerely,

Martin Gleason

Martin Gleason
Director of Legislation

MG:cac

Enclosure

the union that cares

Statement of the
American Federation of State, County, and Municipal Employees

on

S. 462, the Developmentally Disabled Assistance and Bill of Rights Act

Submitted to the
Senate Labor and Public Welfare Subcommittee on the Handicapped

18 March 1975

The American Federation of State, County, and Municipal Employees is pleased to submit this statement on S. 462, the Developmentally Disabled Assistance and Bill of Rights Act, on behalf of the more than 700,000 members of this union, and particularly on behalf of the 80,000 members who work in mental health institutions.

We commend the Subcommittee and its distinguished Chairman for beginning again the process of consideration of this important legislation. While we believe that this legislation the Subcommittee is currently considering contains many progressive and constructive approaches to dealing with the developmentally disabled, we would like to propose certain amendments which we believe would further strengthen this legislation.

State Plans

We are pleased to see a State planning process written into requirements in this legislation for we have found that without adequate and public planning, the provision of care for those with developmental disabilities is often inadequate.

Further, we are pleased that the State plan process (section 114 (a)) contains provisions for both reduction of inappropriate institutional placement and improvement in the quality of care for those for whom institutional care is appropriate (Section 114 (a) (1(and (2)).

During the past two years, AFSCME has conducted a series of Institutes around the country which focused on the question of deinstitutionalization. We found that little or no planning had been done in terms of the care needed by residents after they were discharged from institutions; often no regard was given to the needs or employment of the workers in the institutions and frequently no thought was given to the economic impact of institutional closure on communities.

We therefore, recommend that the Subcommittee ensure by means of this legislation, that patients requiring institutional care are not discharged unless follow-up care is available. Further, we recommend that funds are authorized for the upgrading of institutions for those patients requiring institutional care. In the move toward deinstitutionalization, the needs of those remaining in the institution have too often been overlooked and adequate funds have not been authorized for their care.

Employee protections

Deinstitutionalization can mean the wholesale closure of state institutions for the developmentally disabled, or, at the very least, large cutbacks in institutional staff. A public policy which encourages a change in the method of delivering public services without guaranteeing to the affected employees protections related to their employment status is not responsible.

The quality of mental health care would be adversely affected under these circumstances. Quality care cannot be provided in an atmosphere of uncertainty and fear among employees in public institutions likely to be affected by deinstitutionalization. At a time of shortages in direct care personnel, it would be folly to lose the services and skills of experienced health workers. Further, during this period of rising unemployment, it seems senseless to deprive skilled workers of the opportunity to continue to provide health care.

AFSCME recommends the following language, which is intended to minimize employee hardships and provide continuity both in employment and in the delivery of health care. Similiar language can be found in the Urban Mass Transit Act, and in the Juvenile Justice and Delinquency Prevention Act.

Section 114 (b) (22):

> provide that fair and equitable arrangements are made, as determined by the Secretary of Labor, to protect the interests of employees affected by assistance under this Act. Such protective arrangements shall include, without being limited to, such provisions as may be necessary for --
>
> > the preservation of rights, privileges, and benefits (including continuation of pension rights and benefits) under existing collective bargaining agreements or otherwise; the continuation of collective bargaining rights;

> the protection of individual employees against a worsening of their positions with respect to their employment; assurances of employment to employees of any State or political subdivision of employment to employees of any State or political subdivision thereof who will be affected by any program funded in whole or in part under provisions of this Act, with first priority for employment in community facilities being given to employees of state institutions who become unemployed as a result of the shift from institutional to community care; training or re-training programs, including a planned program for career development and advancement for all categories of personnel.

re-number subsection 22 accordingly as 23

Further, AFSCME recommends that subsection (4) regarding the use of volunteers be amended to ensure that volunteer workers are used to supplement and not supplant positions held by paid employees. We recognize the importance of volunteer personnel but are extremely concerned about the possible use of volunteers to fil regular jobs.

Title II - Bill of Rights for the Mentally Retarded and Other Persons with Developmental Disabilities

AFSCME believes that Title II includes progressive sections on career development programs for employees, staff-patient ratios, and in-service training.

However, in terms of personnel functions, we believe that Section 240 (d) (Subchapter IV-Personnel Policies) should be amended to delete psychological assessment of employees, both initially and annually thereafter. We question not only the necessity for this practice and the criteria by which psychological assessment would be indicated, but also the validity of such tests.

Further, Section 240 (f) provides a mechanism for patients in cases of alleged abuse but does not clearly define the rights of employees in these cases. We urge that this section be amended to provide a mechanism for the employee to present evidence, and be represented by someone of the employee's choosing, in cases of alleged abuse.

We commend the Subcommittee for its recognition in Section 271 (c) (1) (Subchapter XVI-Volunteer Services) of the importance of volunteers supplementing the services of paid employees. We urge the subcommittee to amend the bill, as suggested above, to make the state plan consistent with this subsection.

In conclusion, the American Federation of State, County, and Municipal Employees believes that, with the addition of the amendments we have suggested above, the goal of providing quality care to those with developmental disabilities can best be achieved. We look forward to working with the Subcommittee on this crucial legislation.

THE NATIONAL
easter seal society for crippled children and adults
2023 WEST OGDEN AVENUE, CHICAGO, ILLINOIS 60612
312/243-8400

Please Address Reply To:
Washington Building
1435 "G" St., N.W.
Suite 1031-32
Washington, D.C. 20005
202/347-3066

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Jayne Shover
Executive Director

12 March, 1975

The Honorable Jennings Randolph, Chairman
Senate Subcommittee on the Handicapped
United States Senate
Washington, D.C. 20510

Dear Mr. Chairman:

Enclosed you will find a statement of the National Easter Seal Society for Crippled Children and Adults which, together with this letter, we request be included in the record regarding your consideration of the Developmental Disabilities legislation.

The statement reflects our deep concern about the Developmental Disabilities Act and our support for it. The major point stressed in this statement is the need to clarify the definition of developmental disabilities so that it would relate to functional capacity and not specific types of impairments. We believe that the bill under consideration still poses some of the problems inherent in the bill proposed last year. The focus of our definition is on behavioral deficits resulting from a physical or mental condition which substantially interfere with an individual's ability to acquire normal skills and knowledge and to engage in competitive employment or manage his own affairs. We believe that attempts to list specific types of impairments can never fully reflect the basic intention of this law which is to provide services to better enable every disabled individual unable to acquire normal skills and knowledge to become more independent and self-sufficient. We believe that our definition as set forth in this statement and mentioned above lends itself much more readily to the establishment of a program responsive to the basic goals of the legislation.

We would also like to take this opportunity to indicate to the Subcommittee the importance of community-based care and services in the field of developmental disabilities.

As you know, the National Easter Seal Society operates about 250 outpatient rehabilitation centers serving about 238,000 physically handicapped children and adults, a substantial number of whom are developmentally disabled. We believe that resources such as our centers need to be further developed so that parents of disabled children and disabled individuals have more choices with regard to the placement of disabled people.

We appreciate the opportunity to submit the accompanying statement and this letter and we will be glad to be of assistance to the Subcommittee as it considers this very important legislation. We commend you and the other Members of the Subcommittee for your dedication to this program and to the disabled in this country.

Sincerely,

Edward J. Drake

Edward J. Drake
President, National Easter Seal
Society for Crippled Children
and Adults.

Statement of

National Easter Seal Society for Crippled Children and Adults

Before the Subcommittee on the Handicapped of the
Senate Committee on Labor and Public Welfare

on

S. 462
Developmental Disabilities Act of 1975

March 14, 1975

National Easter Seal Society for Crippled Children and Adults Position on Developmental Disabilities Legislation.

The nationwide Easter Seal Society has a direct interest in proposals under consideration in Congress to modify the Developmental Disabilities Act. With few exceptions our affiliated societies are a major provider of the wide range of diversified services which may be supported under the Act in order to meet the lifetime needs of developmentally disabled persons.

From a perspective developed during 53 years of providing direct services to physically handicapped persons and their families, we have reviewed Public Laws 88-164, 91-517 and 93-45.

The Developmental Disabilities Act stems from Public Law 88-164, the first national commitment to promote the welfare of the mentally retarded. With the passage of the Developmental Disabilities Act in 1970, significant and important changes were made, the most important being the addition of the concept of services.

Definition

As presently written the Act has good intentions but it could have disastrous effects. It has set the welfare of one handicapped child against the other; one parent against the other; one organization against the other. If we have learned anything, it is that the gains we have made in promoting legislation and in obtaining appropriations, have all been made because we have worked together in the attainment of a common cause.

The controversy over the Act lies in the definition of developmental disabilities and its interpretation upon which implementation of the law rests. The broadening of the definition to include cerebral palsy, epilepsy, and other neurological conditions requiring treatment similar to that needed by mentally retarded persons was a remarkably important move. It is unfortunate that in defining developmental disabilities, three diagnostic conditions were listed and that other developmental disabilities were lumped together under the phrase, "other neurological conditions". Specifying the three conditions has resulted in implementing this Act with undue emphasis on mental retardation, epilepsy and cerebral palsy to the detriment of services to other developmentally disabled children and adults. Although the definition was not intended to limit benefits to the three disorders, and because of ambiguity in the wording, in actual practice it excludes services to most other developmentally disabled persons.

The National Easter Seal Society could support the definition that was proposed by the National Advisory Council on Services and Facilities for the Developmentally Disabled, namely:

> "Developmentally Disabled means a disability which 1) is attributable to medically determinable physical or mental impairment; 2) originates before the individual attains

> age 18 and has continued or can be expected to continue indefinitely; 3) constitutes a severe handicap to substantial gainful activity (or in the case of a child under 18, a handicap of comparable severity)."

This definition would eliminate mention of the three diagnostic conditions and focus on the most substantially handicapped.

We would be willing to settle for the definition of the Council rather than further fractionate the forces concerned with the welfare of handicapped persons. If, however, the House Committee were to explore a more conprehensive definition, we would suggest the following:

> "a Developmentally Disabled person is one with a physical or mental condition, originating before age 18 which has continued or can be expected to continue during the life of the individual, and which leads (or has led) to functional deficits which substantially interfere with the individual's ability to acquire normal skills and knowledge, to engage in competitive employment, or to manage his own affairs without public assistance."

Such a definition does not make reference to a "medically determinable" impairment or to a category of individuals. These are not oversights for we believe it is only through an analysis of one's functioning ability that we can determine whether or not he is disabled in contrast to his having a physical handicap. The person who makes the determination should be experienced in the remediation of such disabilities. The concept in this definition is based upon functioning ability rather than upon etiology.

Other Considerations

The original Developmental Disabilities Act did not give guidance to the functions of the State Planning and Advisory Councils on the Developmentally Disabled. This has caused confusion in some States and has prevented these councils from performing in an effective way. We are aware of the problems some Easter Seal Societies have experienced in attempting to work with State Councils for the Developmentally Disabled. It would be useful if the amended legislation could provide more guidance about functions of these Councils.

The National Easter Seal Society wants to go on record as recognizing the Developmental Disabilities Act as a very important piece of legislation. It is our belief that the Act could be strengthened by clarifying the definition. We would like to see a differentiation between that which is a physical condition and that which constitutes a handicap. We would like to see the focus on services and not on diagnostic categories. We would like to see services available to any person with a substantial handicap originating before age 18 who needs such services. We would like to see as much Federal money as possible funneled into these programs so that the impaired in our society need not be permanently handicapped.

STATEMENT

Respectfully Submitted

to

The Subcommittee on the Handicapped

of the

Senate Labor and Public Welfare Committee

on

S.462, "The Developmentally Disabled Assistance and Bill of Rights Act"

In Behalf Of

United Cerebral Palsy Associations, Inc.

66 East 34th. Street

New York, New York 10016

By

E. Clarke Ross

Assistant Director

UCPA Governmental Activities

Washington, D.C.

March 18, 1975

United Cerebral Palsy Associations, Inc. believes that the Developmental Disabilities legislation is absolutely essential to the eventual satisfactory programming for severely and multiply handicapped individuals. The present departmentalized delivery systems have for the most part chosen to ignore the severely and multiply handicapped and the relegate them in their thinking, planning, and service development to some pattern of institutionalized existence out of the mainstream of society.

The DD Act with its targeting of this population for planning and services, its mandate for coordinating service programs across department lines, and its involvement of consumers in the process of planning and decision-making has taken a giant step in helping our most severely disabled citizens move toward achieving their human and civil rights.

Need for Immediate Enactment

The foremost concern of UCPA related to the Developmental Disabilities legislation is that it be extended immediately.

The frustration and despair experienced by State Developmental Disabilities agencies and councils over last year's congressional deadlock has been highly detrimental to the operation of the program. The failure of Congress to enact a permanent extension, and the utilization of stop-gap measures such as continuing resolutions have had adverse effects on the administration of programs for the developmentally disabled within the states. The following are some of the areas that we have readily identified.

1) It has greatly lowered staff - council morale.

2) It has generated a reluctance by States to engage in any long term planning. This is the direct result of uncertainity over congressional priorities and emphasis. Minnesota is awaiting passage before issuing a new State plan.

3) It has forced a delay in the appointment of new council members because of uncertainity over congressional requirements. Council composition is up in the air in North Dakota, Colorado, and Montana.

4) It has postponed any new staffing of State agencies because of the obscurity in statutory requirements. Illinois is holding its approved regional staff positions open awaiting enactment of a DD extension bill. Minnesota DD staff are currently under temporary status for the same reason.

5) Nationally, it has deferred necessary training programs because no new legislation exists. The Developmental Disabilities Technical Assistance System (DD/TAS) has planned a series of orientation sessions of new Council members on the changing focus of the DD program.

This has been delayed until the passage of an extension bill.

6) It has created serious impasses in State government because of confusion over the proper placement and authority of both State DD councils and agencies. A permanent statutory base is a necessity in order to clarify the proper role of the DD program at the state level.

UCPA recognizes that congressional differences over the legislation are substantial. However we feel it is imperative that Congress understand the very harmful effects this deadlock is causing at the State level and the disruptive influence it can have on the delivery of services to the Developmentally Disabled.

Definition

UCPA certainly looks with favor on the addition of "autism" to the definition of developmental disability. We have always supported the broadest interpretation of the term "developmental disabilities" so long as efforts are targeted on the most severely and substantially handicapped individuals. Because of the necessity for interrelating DD programs with other state-federal programs such as social services, Medicaid, and Supplemental Security Income, it seemed wise to us to have all of these programs use the same definition for "disabled." UCP opted to support a slightly modified version of the definition used presently by the Social Security Administration. This definition was also recommended by the National Advisory Council for Developmental Disabilities:

> An individual is considered to be disabled "if he is unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than 12 months (or, in the case of a child under the age 18, if he suffers from any medically determinable physical or mental impairment of comparable severity.)"

UCPA is in agreement with the House Subcommittee on Public Health and Environment in not including "specific learning disability" in the definition. We firmly believe that the Developmental Disabilities legislation must be limited to those persons with severe learning disabilities namely those individuals with substantial disabilities requiring lifetime and comprehensive services. Part G of the Education of the Handicapped Act - Specific Learning Disabilities - offers educational opportunities to the less severely learning disabled. This legislation must be restricted to those individuals severely and multiply involved.

Bill of Rights: Key on Quality Assurance

UCPA believes there must be a compromise reached on the exact provisions of the Bill of Rights for the Mentally Retarded and Other Individuals with Developmental Disabilities, Title II of the Senate extension bill. We believe in the necessity of a strong quality assurance mechanism but we are not wedded to locking the Joint Commission on Accreditation of Hospitals ACFMR standards into statute.

Last year, UCPA participated with several of her sister agencies on the Consortium Concerned with the Developmentally Disabled in drafting an alternative set of standards for Senate professional staff. These alternative standards were accepted and are contained in the Senate bill. UCPA believes they are an appropriate compromise to the existing deadlock over this issue. The alternative standards incorporate four general principles.

1) Performance criteria by which the developmental process of a person with developmental disabilities may be measured.

2) Individualized written habilitation plans for each person with a developmental disability.

3) Designation of a program coordinator to assure a focal point for responsibility for the implementation of the individualized plan.

4) Creation of a protective and personal advocacy system separate from the direct service agency.

Conclusion

UCPA believes the Developmental Disabilities program is a meaningful and fundamental program for the nation's severely and multiply involved disabled persons. We believe the Congress has delayed too long its responsibility for enactment of a permanent and stable program which has proved its effectiveness. UCPA strongly recommends immediate passage of the legislation; the establishment of a functional, noncategorical definition targeted on the most severely and substantially disabled individuals; and a compromise on Title II which will guarantee quality assurance while maintaining flexibility at the service provider level.

NC
MHC
National Council
Community Mental Health Centers

Developmentally Disabled Assistance

and

Bill of Rights Act

(S 462)

Statement for the Record

Submitted to

Subcommittee on the Handicapped

Committee on Labor and Public Welfare

United States Senate

On Behalf of

National Council of Community Mental Health Centers

March 18, 1975

This statement is presented on behalf of the National Council of Community Mental Health Centers (NCCMHC), representing 317 community mental health centers, most of which receive federal funding under the Community Mental Health Centers Act, and all of which receive federal funds from one source or another, and another 119 agencies which are developing CMHC programs or which have a direct interest in community mental health.

The National Council of Community Mental Health Centers (NCCMHC) is pleased to have an opportunity to comment on the extension of the Developmental Disabilities Act. Since 1970, this Act has enabled states and localities to improve and expand services to developmentally disabled persons, a long neglected segment of our population.

The NCCMHC would like to draw attention to a significant trend in the operation of programs under the DD Act; which has been to increase effort and emphasis on deinstitutionalizing developmentally disabled persons. NCCMHC agrees with national authorities on developmental disabilities, and particularly on mental retardation, that for the vast majority of individuals institutional care is inappropriate and inhumane. Further, it is generally agreed that returning institutionalized individuals to the community has a good effect on an individuals rehabilitiation.

The programs provided for under the DD Act have nurtured this trend by stimulating and expanding community-based services and facilities for the developmentally disabled. It is NCCMHC policy to encourage deinstitutionalization where such programs are consistent with the capacities of the individuals concerned and where adequate provision has been made for alternative care and service in the community.

S 462 contains many provisions which will not only strengthen the DD Act in general, but will also strengthen the trend in the deinstitutionalization of the developmentally disabled. NCCMHC supports the extension of the DD Act as projected in S 462 but with a reservation concerning the promulgation of standards for institutions caring for the mentally retarded contained in Title II.

Extension of DD Act

In reviewing this legislation, NCCMHC finds it significant that S 462 provides for a five-year extension of the programs authorized by the DD Act. The House bill, HR 4005, only provides for a three-year extension.

NCCMHC supports the Senate provisions providing for a five-year extension and advance funding which recognizes that states must have a long range perspective and a continued assurance of funding in order to carry out the comprehensive planning mandated by the Act.

A two-year extension does not adequately allow for well thought out planning activities, program stability, and continuity in the provision of services to developmentally disabled persons. If increased activities for the responsible state agencies, are to be mandated then the legislation must provide for a means whereby states can realistically follow through on the newly mandated responsibilities. The five-year extension and advance funding provisions of the Senatebill acknowledge the increased responsibilities.

State Grant Program

Consistent with the five-year extension provided for in S 462 are the provisions for the state grant program. This program, which provides the basic funding mechanism for improving services to the developmentally disabled population, is essential if states and localities are going to continue serving dd persons in a manner consistent with need.

NCCMHC concurs with the Senate provision requiring agencies receiving assistance under the Developmental Disabilities Act to have affirmative action plans for the employment and advancement of handicapped individuals.

Authorizations

The authorization levels in the Senate bill are much more realistic than those in the House bill, especially if the states are to adequately perform the increased responsibilities mandated by this legislation.

The House authorization levels would not enable states to provide for and expand service and maintain adequate planning levels, particularly in light of the new requirements for an emphasis on deinstituionalization.

State Plans

NCCMHC also strongly supports those provisions in the Senate bill which would strengthen state plan requirements in the direction of encouraging more comprehensive planning by states for persons with developmental disabilities.

Specifically, S 462 strengthens the state plan requirements by mandating that plans must include provisions designed to:

- reduce and eventually eliminate inappropriate institutional placement of persons with developmental disabilities

- provide early screening, diagnosis, and evaluation of developmentally disabled infants and preschool children

- support community programs as alternatives to institutionalization utilizing the personnel and resources in related community programs

The House bill contains a similar provision by adding a requirement that states plan:

> "...to eliminate inappropriate placement in institutions of persons with developmental disabilities, and to improve the quality of care and the state of surrounding of persons for whom institutional care is appropriate."

In addition, the House bill contains a provision that states use first at least 10% and then at least 30% of their available monies for deinstitutionalizing as many of those with developmental disabilities as is possible.

Although implicit in the House bill, the Senate bill which NCCMHC supports makes explicit the mandate of the legislation, as regards deinstitutionalization, by requiring state plans to include:

- planning and support for eliminating inappropriate placement in the first place through provision of early screening, diagnosis, and treatment

- planning for the development of suitable programs for persons with developmental disabilities in their own communities

NCCMHC feels it is important that legislation extending the DD Act make specific that community programs of support for persons with developmental disabilities are to be supported and that inappropriate institutionalization be reduced and eventually eliminated.

However, deinstitutionalization of persons with developmental disabilities, without ensuring community programs of support, is not only inappropriate but inhumane. Consequently, it is necessary that the more specific language in the Senate bill be enacted.

Project Grant Authority

Under existing law, the project grant authority for special projects and demonstrations to improve and integrate care for dd persons has been inadequate. NCCMHC welcomes the Senate provisions which would considerably expand grants for special projects for services to persons with developmental disabilities.

This new project grant authority would greatly stimulate and expand programs which assist handicapped individuals who are disadvantaged or multi-handicapped. These demonstrations provide models for systems of community-based care which provide a matrix of supportive services necessary to maintain a person with developmental disabilities in the community.

NCCMHC also supports the provision in the Senate bill which continues the authority for national significance grants to states and other public or nonprofit agencies for demonstration projects designed to coordinate and utilize available community resources for services to developmentally disabled individuals.

In the past, these projects have assisted in meeting the needs of the disadvantaged with developmental disabilities and have demonstrated improved techniques for service provision.

Continuation of this authority guarantees that the necessary work of improving and integrating the service delivery system to persons with developmental disabilities will be performed. With an increasing emphasis on deinstituionalization these grants will be necessary to further demonstrate integrated service models and effective coordination of community resources to persons with developmental disabilities.

University-Affiliated Facilities (UAFs)

NCCMHC concurs with the Senate bill which provides for modifications in the UAF program designed to faciliate greater coordination with the other state developmental disabilities programs and which would require UAFs to establish priority goals (as outlined in S 462) as a condition for assistance.

The demonstration and training grants which the UAF program provides for are essential and compliment functions of the other programs provided for under the Act. Targeting the UAF program toward the goals which S 462 establishes for the state developmental disabilities programs will not only facilitate greater access to these services and resources for developmentally disabled persons but will also enhance the total system of care provided for under the Act.

State Councils

The NCCMHC is pleased to see that S 462 would strengthen the role and revise the functions of the State Councils.

By mandating State Council responsibility for overall consideration, planning, and development of all programs involving the developmentally disabled the much needed centralization of authority for programs to this segment of the population is secured and accountability for dd programs is increased.

In addition, relieving the State Councils of the responsibility for administration of grants (and the time consumed by such activity), is consistent with the mandate that these councils prepare the state plan, establish funding priorities, and evaluation implementation of the state plan. S 462 recognizes the importance of the councils' planning function and the time required to adequately plan for the developmental disabilities community through the provision which relieves councils of this task.

The required 20% set-aside of a states allotment for State Planning Council personnel is further assurance that councils will have the capacity to fulfill their planning, development, and evaluation responsibilities.

As the State Council is given a much more substantial lead role in determining the general direction and goals of the program, so too is there need to facilitate communication between those who plan, providers, and consumers.

The provisions of the Senate bill which require public representatives on the state councils is important. This provision will not only facilitate consideration of alternative modes of care but will also forge stronger linkages in the total system of care to persons with developmental disabilities. The desired changes in the role of the State Councils would be greatly strengthened by passage of the Senate bill.

Evaluation

A critical component of a comprehensive planning approach, which the NCCMHC strongly advocates, is an accurate assement of existing services and resources.

We support the provisions in S 462 which would require HEW to develop a model evaluation system which the states will implement. Effective comprehensive planning requires that we have assessed the adequacy of services currently provided and that we develop and have criteria by which progress can be measured over time.

Efficient utilization of resources and the overriding need to provide necessary services germane to persons with developmental disabilities mandates this.

Quality of Care

In the past, NCCMHC has encouraged improvements in the quality of care, habilitation, and rehabilitation for those for whom care is appropriate.

NCCMHC is aware of the inadequate and all too often dehumanizing conditions which prevail in many of our institutions for the mentally retarded. The need for an imposition of standards on the appropriate parties is considerable if current conditions are to be upgraded.

However, NCCMHC believes that a statutory approach to standard-setting, such as that contained in Title II, is both unwise and impractical.

Over the last decade, the manner in which we think about retarded people and how best to provide service for them has changed considerably. The recent trend towards rejecting institutional/custodial modes of care to more normalized community living and care is testimony to this.

This legislation would strengthen current trends in this direction by mandating further deinstitutionalization of persons with developmental disabilities. This will surely have implications for both institutional and non-institutional standards of care. NCCMHC's concern is that the legislative process is too cumbersome to permit a timely revision of these standards to reflect current experience and thinking in the field. This would ultimately impact on those the provision is designed to protect - persons with developmental disabilities.

The NCCMHC respectfully requests that the subcommittee consider an alternative approach to standard setting. An alternative would be to direct the Secretary of HEW to promulgate standards through the regulatory process and/or include a limited waiver authority for the Secretary.

We applaud the Subcommittee's continuing efforts to ensure reasonable standards of care for this segment of our population, but respectfully submit that the problem can be properly addressed in an alternative fashion.

In conclusion, NCCMHC feels that many of the desired changes sought and needed in programs under the DD Act would be secured by passage of S 462.

As you well know, the DD Act expired June 30, 1974. With a lack of authorizing legislation, many uncertainties are cast over those mandated to provide service to and persons with developmental disabilities. We strongly urge this subcommittee to act quickly on this much needed legislation and hope that it can be enacted without compromising the principles outlined above.

STATEMENT

ON

DEVELOPMENTALLY DISABLED ASSISTANCE

AND

BILL OF RIGHTS ACT

S. 462

Respectfully Submitted to:

The Subcommittee on the Handicapped

of the

SENATE COMMITTEE ON LABOR AND PUBLIC WELFARE

Presented By:

THE NATIONAL ASSOCIATION FOR RETARDED CITIZENS

March 18, 1975

The National Association for Retarded Citizens is again pleased to have the opportunity to present this statement on the Developmentally Disabled Assistance and Bill of Rights Act. Our organization was very disheartened when this Committee and your counterparts in the House were not able to reach agreement in conference on your Developmental Disabilities bills at the end of the 93rd Congress. We are delighted and greatly encouraged, however, that you have seen fit to make the Developmental Disabilities legislation among the first to be considered in this new Congress.

This statement, in general terms, contains our positions and recommendations designed to make the Developmental Disabilities program a better vehicle for developmentally disabled citizens to obtain necessary services.

Length of Extension of the Legislation

The National Association for Retarded Citizens supports the Senate bill, which extends the Developmental Disabilities program for five years. This program needs to be stabilized as soon as possible. We know this program is still in its infancy. State Councils have just recently become smooth working groups. Provider agencies and state agencies are now recognizing the importance of this program.

The failure of the last Congress to enact extending legislation has slowed this progress considerably. Since this program has lacked new authority, increased appropriations have not been possible. A five year extension will greatly enhance the ability of Developmental Disabilities Councils to carry out their activities.

Definition of Developmental Disabilities

Our organization endorses the retention of the definition contained in the present Act. We oppose the inclusion of learning disabilities in the definition of developmental disabilities, as contained in the Senate bill. We recognize the great need to provide services to the learning disabled population. The very term, "learning" disabled, however, connotes difficulty in the educational process. The vast majority of these children must be served through the public school system. We envision this need as an educational one, which should not be a Developmental Disabilities role except as the State Council reviews the special education state plan.

The National Association for Retarded Citizens has and will continue to support increased appropriations for programs for the learning disabled under the Education for the Handicapped Act.

In addition to the limitation to educational service needs, we feel that this disability category does not meet another criteria in the existing developmental disabilities definition, namely, that the disability "has continued or can be expected to continue indefinitely."

We also note that the Administration has chosen not to include the learning disabled in their Developmental Disabilities bill.

Federal Matching

The National Association for Retarded Citizens strongly urges you to retain the present 75% Federal matching requirement. The Senate matching provision (70%) and the Administration's declining matching provisions would greatly inhibit and possibly prohibit states and provider agencies from participating in this worthwhile program. This is particularly true in these times of tight budgets.

Consumer Representation on Developmental Disabilities State Councils

Section 115(d) of the Senate bill contains language that would prohibit officers of any organization which receives funds or provides services pursuant to this Act, from membership as consumers on the state planning councils. The National Association for Retarded Citizens opposes this provision. In our opinion, the intent of having consumers and their representatives on the councils is to allow other council members the opportunity to hear and see first-hand, the needs of the developmentally disabled. At the same time, it allows direct input by developmentally disabled individuals and their representatives at council meetings.

The mentally retarded, particularly those that meet the definition of developmental disability have difficulty in articulating their needs and participating in the process of council business. For this reason, the definition of consumer in the existing regulations includes representatives of the developmentally disabled. Most of the officers of Associations for Retarded Citizens and other similar organizations are parents of these individuals,and are usually the most involved persons in that organization, and can best articulate the needs of the people they represent.

To deny these individuals the opportunity to serve on Developmental Disabilities Councils will rob the councils of valuable consumer representation and leadership. We urge this provision be removed.

We do support, however, the provision that employees of these organizations not serve as "consumer representatives."

Bill of Rights Provisions

Our organization has a deep commitment toward the purpose as stated in Title II of S. 462. The Policy Statements on Residential

Services adopted by our Board of Directors in October 1968, addresses the issues of the denial of civil rights, unnecessary, inappropriate and prolonged institutionalization, the lack of maintaining standards and the need for alternative community care, all of which are addressed in Title II. To this end, the National Association for Retarded Citizens was a lead agency of the Accreditation Council for Facilities for the Mentally Retarded which developed the two sets of standards incorporated as Parts C and D of Title II.

It is our opinion, however, that locking these new, relatively untested standards into law is a serious mistake. These standards will need constant revision. To have to amend the Developmental Disabilities Act to accomplish this will be tedious and use up much of the Congress' valuable time. At the same time, we recognize the intent of this Title as very important.

We recommend adopting Part B of Title II in some revised form that will allow providers of service to the developmentally disabled, state agencies and the Federal Government to establish and implement quality assurance systems. In order for this to be accomplished, a reasonable timetable for compliance must be flexibly structured and most important, the Congress must authorize specific sums of money for residential and community-based facilities to be upgraded to achieve compliance and for the Secretary to develop such systems.

We urge this Committee not to enact Title II of the Senate bill, as presently written, into law.

Authorizations

We strongly endorse the Senate authorizations for the formula grant program. We also support the Senate authorizations of $20 million for the University Affiliated Facilities programs.

We recommend the consolidated special project grants be authorized at $18.5 million for the first year, with an additional $2.5 million added each subsequent year.

Consolidated Special Project Grants and Projects of National Significance

The National Association for Retarded Citizens strongly encourages this Committee to enact the Special Project Grant provision in the Senate bill at the authorization level contained in our recommended authorizations.

Additionally, we support a 30% set aside for projects of national significance under the special project authority, rather than a 10% set aside under the formula grant program.

Our organization hopes that the above recommendations will be helpful to you in your deliberations. The Developmental Disabilities program is a vital one that sets in place, at the State level, a meaningful planning mechanism designed to pull together Federal, state and local resources to maximize their impact on developmentally disabled citizens. In these hard economic times, maximum utilization of these resources should be utmost in our minds. We urge you to enact this legislation as rapidly as possible in order for the State Developmental Disabilities Councils to renew their activities and in order that thousands of developmentally disabled persons can begin to receive desperately needed services.

This Committee is to be congratulated for its past efforts on behalf of the developmentally disabled citizens of our country, and we wish you well in this new session.

AMERICAN DENTAL ASSOCIATION

WASHINGTON OFFICE • SUITE 1004 / 1101—17TH STREET, N.W. • WASHINGTON, D.C. 20036 / Phone [illegible]

March 18, 1975

The Honorable Jennings Randolph
Chairman
Subcommittee on the Handicapped
5121 Dirksen Senate Office Building
Washington, D.C. 20510

Dear Senator Randolph:

I am writing to express the views of the American Dental Association concerning S. 3378 the Developmentally Disabled Assistance and Bill of Rights Act, particularly with respect to the dental care provisions in Title II of the proposal, the "Bill of Rights" for the mentally retarded.

We believe that the comprehensive dental standards outlined in section 261 are well-conceived, and if attained will result in a professionally sound and effective dental health treatment program for residents of facilities for the mentally retarded and others with developmental disabilities. The authors of the bill are to be commended for the thoroughness of their understanding of proper dental care procedures.

Unfortunately we do not have sufficient information to enable us to comment meaningfully on two aspects of the dental provisions of this bill which we feel deserve considerable study. These same two questions would apply to the other areas for which standards are established. One of these relates to the cost of implementing the comprehensive dental program as outlined in the standards in all appropriate facilities in the U.S. The second question relates to the practical possibility of actually establishing such a program in each facility within five years.

Although the goals of the legislation are extremely desirable, it would appear that questions as to overall cost and the availability of equipment and manpower must be realistically answered before a program as comprehensive and as specific as that proposed in this bill can be implemented. For these reasons, the Committee may wish to include language in the legislation permitting some sort of waiver or partial waiver of the standards where this can be justified with respect to individual facilities.

It is respectfully submitted that these comments be included in the hearing record on S. 3378. If any further assistance can be provided during your deliberation, please do not hesitate to let us know.

Sincerely yours,

Paul W. Kunkel

Paul W. Kunkel, Jr., D.M.D
Chairman
Council on Legislation
American Dental Association

PWK:jf

MAR 17 1975

UNITED CEREBRAL PALSY ASSOCIATIONS, INC. • 66 EAST 34th STREET • NEW YORK, NEW YORK 10016

Reply To:

BELLEVUE HOTEL, 15 E STREET, N.W.
[illegible]
[illegible]

Harold A. Benson, Jr. (212) 889-6655
Director
Governmental Activities Office

March 13, 1975

The Honorable Jennings Randolph
Chairman, Senate Subcommittee on
the Handicapped
Dirksen Senate Office Building
Room 5121
Washington, D.C.

Dear Senator Randolph:

United Cerebral Palsy Associations, Inc., applauds recent Congressional efforts to increase the responsiveness and effectiveness of the Developmental Disabilities program. If these congressional objectives to better serve, those with developmental disabilities are to be adequately achieved, HEW's Division of Developmental Disabilities must be strengthened and reinforced on a continuing basis.

We believe the sincerity and leadership of Assistant Secretary Stanley Thomas has vastly improved the visability, focus, and morale of the Developmental Disabilities office. However, more is needed. A greater effort should be made.

We have witnessed a startling demise in the actual number of staff positions. In December 1967, the former Division on Mental Retardation had a staff of 60 persons which declined to 33 by February 1970. In June 1971, when the Division on Developmental Disabilities began to actively implement P.L. 91-517, a staff of 28 was in place. Today, (December 1974) we see a staff of 18, a two-thirds reduction from 1967.

The Congressional proposals would expand the Division's administrative oversight responsibilities, would expand the Division's responsibilities and effectiveness in serving an improved National Council, would require promulgation of regulations within 90 days of enactment, would increase special project activity, and would require the Division, in consultation with the National Council, to develop an elaborate model evaluation system and to develop a plan for implementation by the states. UCPA supports these initiations but emphasizes that adequate staff must be in place to guarantee their success.

UCPA has always been concerned with the breakdown in communications between central office - regional office - and state agencies and councils. In our February 8, 1973 Senate testimony we emphasized the fact that "there seems to be no clear cut, consistent method to

LEONARD H. GOLDENSON, CHAIRMAN OF THE BOARD • JACK HAUSMAN, VICE CHAIRMAN • [illegible], VICE CHAIRMAN • [illegible], PRESIDENT • [illegible], M.D., VICE PRESIDENT, MEDICAL AFFAIRS • [illegible], EXECUTIVE DIRECTOR

channel information from the HEW central office to the Regional offices and then to the state offices and state councils". We firmly believe that HEW regional offices must be so organized to guarantee the integrity and identity of the Developmental Disabilities program.

UCPA notes with interest the placing of the Director of the Office of Rehabilitation Services (DORS) in a position of direct responsibility to the Regional Commissioner. UCPA recommends that the appropriate Developmental Disabilities staff have direct access to the Regional Commissioner following the DORS model.

Successful implementation of the new DD legislation will be highly dependent on a viable and strong administrative structure. This structure must be so organized as to increase staff capability, especially related to evaluation to upper level management, especially in matters concerning budget decisions and long range planning; and to increase the recognition of the Division's planning and coordination functions.

UCPA is hopeful that the sincere efforts and concerns of the Congress with the future of the Developmental Disabilities program will be reinforced by a strong administrative endeavor. Thank you for your consideration.

Sincerely,

Ada Gruber

Mrs. Ada Gruber
Chairman
UCPA Governmental Activities
Committee

AG/pab

cc: Subcommittee Members

Calendar No. 155

94th Congress } SENATE { Report
1st Session } { No. 94-160

DEVELOPMENTALLY DISABLED ASSISTANCE AND BILL OF RIGHTS ACT

May 22, 1975.—Ordered to be printed

Mr. Randolph, from the Committee on Labor and Public Welfare, submitted the following

REPORT

[To accompany S. 462]

The Committee on Labor and Public Welfare, to which was referred the bill (S. 462) to provide assistance for the developmentally disabled, establish a bill of rights for the developmentally disabled, and for other purposes, having considered the same, reports favorably thereon with amendment(s) and recommends that the bill as amended do pass.

Purpose

The principal purpose of title I of S. 462 is to extend and improve the programs initiated under the Developmental Disabilities Services and Facilities Construction Act (Public Law 91-517) for five years beginning July 1, 1974.

It is the Committee's intent to insure the continued targeting of funds and resources to developmentally disabled individuals through a combination of national, State, and local efforts. To this end, this legislation is designed to assist the States in developing a comprehensive plan which will bring together all available resources so that such persons may be served in the most effective, efficient way. Further, it will add a new program to facilitate the achievement of standards by residential and community facilities in order to protect the rights of mentally retarded and other developmentally disabled persons.

The intent of title II is not only to improve care in residential facilities but also to minimize inappropriate admissions and to stimulate States to develop alternative programs of care for mentally retarded and other developmentally disabled persons. It is clear that the provision of adequate and humane care in large State institutions alone is not an adequate answer to the problem. Other initiatives must include cutting off the flow of residents into the institution through *the development of community alternatives. Thus, title II is directed* toward these goals.

NEED FOR LEGISLATION

As defined in S. 462, developmental disabilities are those disabilities which originate in childhood and are attributable to mental retardation, cerebral palsy, epilepsy, autism, severe specific learning disabilities, or to certain other conditions. Such disabilities continue indefinitely and constitute a substantial handicap with respect to one's ability to function adequately for personal or social needs.

Over 6 million American citizens suffer from mental retardation; those with epilepsy number over 2 million; 750,000 suffer from cerebral palsy; those suffering from autism are estimated at 80,000; and approximately 1 percent of the school-age population suffers from specific learning disabilities toward the severe end of the continuum. A large percentage of all these citizens are so severely disabled as to require a lifetime array of services to reduce dependency or to develop potential abilities for personal and social functioning. Developmentally disabled persons frequently are afflicted with two or more overlapping conditions: for example, approximately 35 percent of those afflicted with mental retardation suffer additional severely handicapping conditions such as cerebral palsy, epilepsy, deafness or blindness. Obviously, these individuals require programs designed to provide for specific and multiple problems.

The concept underlying the Developmental Disabilities Act passed in 1970 was that there was a great need for better planning for services to developmentally disabled individuals. That legislation, therefore, used its limited funding to fill gaps in existing generic and specialized services, to extend the reach of currently available services to new groups of individuals, and to integrate service resources in a State to meet the changing needs of developmentally disabled persons. The Act also provided for interdisciplinary training programs in institutions of higher education, for grants for projects of national significance, and grants for the construction and operation of University-Affiliated Facilities (UAF's) for the developmentally disabled.

Encouraging but limited progress has been made under the present law. There has been a limited emphasis on community care and refinements in institutional programs; there are inadequacies in various States in terms of advocacy, early intervention, developing alternatives to institutionalization, improvements in institutional services and environment, transportation to and from services, and identification and tracking of clients. In relation to the magnitude of need, accomplishments in these areas have barely scratched the surface.

Further, in reviewing (at the request of the Subcommittee on the Handicapped) the programs supported under the present Act, the General Accounting Office found (a) that wide variation existed between programs for developmentally disabled persons in the various States; and (b) that programs within the same State, supported either by funds for the University Affiliated Facilities or by the grants-in-aid to the States program, frequently were administered and operated without coordination and with different goals.

The Committee has determined that there is a need for continued Federal concern for the treatment and dignity of developmentally disabled citizens in terms of appropriate legislation and adequate levels of financial support. In particular, the Committee believes that there is a need for a clear exposition of the purposes for which support should be provided under the authorities of the Act and that the purposes and goals of programs located in University-Affiliated Facilities and those located in the community should be the same.

To achieve this goal, the Committee bill is written so that the States must expend more effort in coordinating planning for the delivery of services to developmentally disabled individuals. S. 462 establishes a cooperative relationship between the State Planning Councils and State agencies responsible for the implementation of the State plans. The Committee believes that this new relationship will be more effective in the planning and catalytic deployment of funds so that an integrated and efficient delivery of services to developmentally disabled individuals can be achieved.

In brief, title II of S. 462 reflects the Committee's increasing concern about persons who are institutionalized because they are developmentally disabled. In his statement before this Committee, Dr. Robert Cook commented as follows:

> The institutionalized mentally retarded are the most neglected of all persons in our society. They have been subjected to ethical and legal abuses, with loss of rights, both civil and personal, frequently occurring without even a semblance of due process. Such abuses have recently been recognized by class action suits through the courts and some change can be expected. Some of the dehumanizing aspects result from gross inadequacies of institutional facilities, programs and personnel, and are not a necessary consequence of residential care.
>
> There is no question but that residential care outside the parents' home is necessary in some instances. Families for a host of reasons may not be able to cope. Families may disintegrate from illness; physical, mental, or social. The retarded or disabled may present management problems far greater than any parent can take care of, or the retarded may age and move into adult life without parental care. Thus, we will need residential care for many, many years to come.

The last four years have seen a dramatic increase in public awareness of the needs of institutionalized mentally retarded or developmentally disabled persons. This has been highlighted by scandals in a number of institutions, by court cases, and by some excellent work done in the mass media. Testimony before this committee persuasively demonstrated that implementation and enforcement of minimum standards of care in institutions for the developmentally disabled are urgently needed and that the Federal government can and should play a significant role in upgrading the care and services provided to developmentally disabled persons in public and other facilities which operate with Federal funds.

HEARINGS

On February 8, 1973, the Subcommittee on the Handicapped of the Committee on Labor and Public Welfare held hearings on S. 427, a bill to provide for the extension of the Developmental Disabilities Services and Facilities Construction Act.

More than 25 witnesses testified in support of S. 427 and related legislation. A considerable number of professional and consumer organizations were represented. Among those groups testifying were the National Society for Autistic Children; the National Association for Retarded Children; National Association of Private and Residential Facilities for the Mentally Retarded; Muscular Dystrophy Association of America; American Speech and Hearing Association; United Cerebral Palsy Association, Inc.; American Physical Therapy Association; National Easter Seal Society for Crippled Children and Adults; National Association for Mental Health, Inc.; and National Association of State Mental Health Program Directors.

Hearings were concluded when testimony was given on May 1, 1974, concerning S. 3378, the "Developmentally Disabled Assistance and Bill of Rights Act". Witnesses at this hearing included Mr. Stephen Kurzman, Assistant Secretary for Legislation, Department of Health, Education, and Welfare; and Mr. James Dwight, Administrator, Social and Rehabilitation Service, Department of Health, Education, and Welfare.

Because S. 3378 was not enacted, the Chairman of the Subcommittee on the Handicapped, Senator Jennings Randolph, reintroduced an identical bill in the 94th Congress with bill number S. 462. On March 18, 1975, the Subcommittee held hearings on S. 462 and on S. 1194 (a measure which Senator Stafford, ranking minority member of the Subcommittee, had introduced by request). Testifying at that hearing was Stephen Kurzman, Assistant Secretary for Legislation, Department of Health, Education, and Welfare; Peter Franklin, Special Assistant to the Secretary; and Francis Lynch, Director, Office for Developmental Disabilities, Office for Human Development.

BACKGROUND

On February 5, 1963, President Kennedy sent a message to the Congress proposing two major new programs. He stated in that message:

> In an effort to hold domestic expenditures down in a period of tax reduction, I have postponed new programs and reduced added expenditures in all areas when that could be done. But we cannot afford to postpone any longer a reversal in our approach to mental affliction . . . We can procrastinate no more. The national mental health program and the national program to combat mental retardation herein proposed warrant prompt congressional attention.

The legislative package contained in President Kennedy's proposal was the result of recommendations of the President's Panel on Mental Retardation, which he had appointed in 1961, when he first directed that new approaches in these areas should be developed. The results of the President's recommendations for new programs were embodied in Public Law 88–156, a bill which launched a special Federal program of comprehensive maternity and infant care projects aimed at high-risk mothers, and Public Law 88–164, which launched the first major Federal program for the construction of facilities for the mentally ill and mentally retarded.

The Developmental Disabilities Services and Facilities Construction Act (Public Law 91–517) was signed by President Nixon in 1970 and was an outgrowth of, and an amendment to, Public Law 88–164. In the interim between the passage of the two laws, modern buildings were constructed, demonstration programs were successfully conducted, and manpower was trained. Benefits from the mental retardation program were being felt. Still, large groups of handicapped persons with conditions needing similar services were excluded.

Public Law 91–517 changed the original 1963 Act in several different ways:

1. It broadened the population to be served by the legislation, including not only mentally retarded persons, but also those suffering from cerebral palsy, epilepsy, and neurological conditions closely related to mental retardation;

2. Title I, Part B of Public Law 88–164 had authorized project grants for the construction of University-Affiliated Facilities for the mentally retarded. The new law extended this program for three additional years, expanded it to include other developmental disabilities besides mental retardation, replaced the term "clinical training" with the term "interdisciplinary training" to emphasize the cross-disciplinary nature of the UAF program, and authorized a new program of project grants for operational support for programs in facilities of this type.

3. Title I, Part C of Public Law 88–164 created authority for construction of community mental retardation facilities. Public Law 91–517 replaced that authority. The new law mandated a Federal-State formula grant program to (a) assist the States in developing and implementing a comprehensive State plan to meet the needs of the developmentally disabled; (b) to assist public or other nonprofit agencies in the construction of facilities used in the provision of services; (c) to provide services to persons with developmental disabilities; (d) to support costs of planning, administration, or technical assistance to States and local agencies; (e) to train specialized personnel needed in this area; and (f) to provide for the demonstration or development of new techniques for the delivery of services.

Public Law 91–517 also established a National Advisory Council on Services and Facilities for the Developmentally Disabled to advise the Secretary with respect to regulations promulgated pursuant to enactment of Public Law 91–517 and to study and evaluate programs authorized by Part C under that law.

In June 1973, thirteen major authorizations for Federal programs (including the Developmental Disabilities program) expired simultaneously. They were placed under an umbrella amendment to the Public Health Service Act and given a one-year extension. This legislation expired at the end of fiscal 1974, and the Developmental Disabilities Services and Facilities Construction Act programs are being continued under a Continuing Resolution until June 30, 1975.

The 1970 Act has provided for the commingling of funds under this program with those of other programs to facilitate the development of comprehensive services for developmentally disabled persons; there has been a combination and integration of the efforts in both specialized and generic services of agencies representing diverse areas such as health, welfare, education and rehabilitation, without imposing a set pattern of services on any one State.

The formula grant program (Part C) has operated through two main mechansims: designated State agencies and State Planning and Advisory Councils. One or more State agencies have been chosen to administer or supervise a State plan. This plan is to be submitted to the Secretary of the Department of Health, Education, and Welfare for approval and is to include a description of how other State-Federal programs provide for developmentally disabled persons and how any new programs will complement and augment, not duplicate, existing programs. At least nine Federal programs are taken into account: vocational rehabilitation; public assistance; social services; crippled children's services; education for the handicapped; medical assistance; maternal and child health; comprehensive health planning; and mental health.

At the same time, a State Planning and Advisory Council has been charged with setting the pace for the direction, development and growth of the program. Membership of the State Planning and Advisory Council has included representatives of the principal State agencies, local agencies, non-governmental organizations and citizens groups, and representatives of consumers of services.

Since the enactment of Public Law 91–517, the States have spent 73.1% of their Federal funds for the provision of services, and 8.1% for construction. The remainder, 8.8%, has been used for planning and administration. Over the three year period from 1971 to 1974, $58.9 million in Federal funds have been spent for services, $15.1 million for planning and administration, and $6.8 million for construction of facilities.

The developmental disabilities program has been in actual operation for less than three years in most jurisdictions, but the soundness of the basic legislation has been amply demonstrated. The Committee believes, however, that S. 462 will redirect the programs so that more developmentally disabled persons will receive direct benefits of the program.

Summary of Major Provisions

TITLE I

1. DEFINITION OF DEVELOPMENTAL DISABILITIES

The definition of a "developmental disability" under the 1970 Act limited the term to those suffering from mental retardation, cerebral palsy, epilepsy, and other neurological conditions. The Secretary of the Department of Health, Education, and Welfare, in regulations developed pursuant to enactment of the 1970 law, narrowly construed this definition so that it in effect applied only to mental retardation, cerebral palsy, and epilepsy. In the opinion of many in the professional community, this restricted definition omitted a large number of persons who were in fact developmentally disabled and who could greatly benefit from the planning and services mandated by the Act. Thus, the Committee has changed the definition by adding autism and severe specific learning disabilities. It also includes any other condition of an individual found to be closely related to mental retardation as it refers to general intellectual functioning or impairment in adaptive behavior or to require treatment similar to that required for mentally retarded individuals. The Committee retained language stating that the disability had to (1) originate before the individual became 18; (2) continue indefinitely; and (3) constitute a substantial handicap to an individual's ability to function normally in society.

The Committee included autism and severe specific learning disabilities after long and careful deliberation. Since it is the Committee's intent that funds authorized by this legislation are to be used primarily for planning and coordination, it will not require a substantial increase in funds to plan and coordinate services for autistic persons and persons having severe specific learning disabilities as well as to plan and coordinate services for persons with mental retardation, cerebral palsy, and epilepsy.

Autism has been the most neglected of the childhood disabilities, partly because of ignorance and misunderstanding. Autistic persons, if they are given the medical, educational, and vocational intervention to which they have a right, can become functional and productive members of society. They have needs which are similar to those of individuals with mental retardation, cerebral palsy, and epilepsy; therefore, when services are provided under this Act, services for autistic persons can be integrated into on-going or planned programs for other developmentally disabled persons without significantly increasing costs. Even where additional expenditures are required, the Committee believes that we must provide those services which have so long been lacking.

When the Committee includes persons with severe specific learning disabilities, it intends to help only those who are most seriously in need of assistance, i.e. those who meet the criteria that the disability (1) must have originated before age 18; (2) is expected to continue indefinitely; and (3) constitutes a substantial handicap to such individual's ability to function normally in society. Only those whose specific learning disabilities are toward the severe end of the continuum will meet the definition contained in this Act.

II. UNIVERSITY-AFFILIATED FACILITIES (PART A)

A. History

Public Law 88-164, enacted in 1963, intended University-Affiliated Facilities (UAF's) to be clinical facilities associated with an institution of higher education; they would serve three main functions:

1. Provide clinical training of physicians and other specialized personnel to serve the mentally retarded;
2. Demonstrate new techniques (exemplary services) to diagnose, treat, educate, train and care for the mentally retarded;
3. Provide inpatient and outpatient services for the mentally retarded.

Subsequent legislation introduced the term "interdisciplinary training" to emphasize that UAF training programs should include doctors, social workers, pediatricians, therapists and professional personnel from other disciplines who would work as a team, learning what each has to offer in terms of services.

B. Demonstration and Training Grants

Section 102 of S. 462 continues this program and a system of demonstration and training grants to be used for covering part of the cost of administering and operating demonstration facilities and interdisciplinary training programs for professional personnel. Such facilities and programs are connected with an institution of higher education and are designed primarily to serve persons with developmental disabilities. The Committee has authorized $25 million for FY 1975 and each of the four succeeding fiscal years for these grants.

Any facility desiring to receive a grant must establish goals similar to and consistent with those required in the State plans mandated by Section 114 of S. 462. Therefore, in addition to training physicians and specialized personnel needed to provide services to developmentally disabled persons, UAF's must establish as priority goals: (1) deinstitutionalization of persons with developmental disabilities whenever possible; normalization outside institutions; development of community-based programs; and follow-up services for persons who leave institutions; (2) early screening, diagnosis and evaluation of infants and preschool children who suffer from developmental disabilities (this includes maternal care, developmental screening, home care, infant and preschool stimulation programs, parent counseling and training); (3) services for adults, including counseling, client program coordination, follow-along services, protective services, and personal advocacy services; and (4) normalization of institutional life. There is an emphasis upon the ability and commitment of the UAF program to provide services in the community which are not available under other laws to persons with developmental disabilities.

The Committee feels that the prime reason for the creation of the UAF's was to serve the developmentally disabled community through the interdisciplinary training of professional personnel and that the UAF's must become more responsive to the goals of the Developmental Disabilities program. Because they have been funded from multiple sources, most of their funds ($14.6 million in 1973) have come from the Maternal and Child Health Service; and they have not had any specified set of goals other than interdisciplinary training. There has been a great deal of confusion as to their exact role. Instead, they have responded to the varying dollar amounts contributed by Maternal and Child Health, the Bureau of Education for the Handicapped, the National Institutes of Health, Vocational Rehabilitation, organizations and universities. The inevitable result has been a lack of focus for UAF programs, a lack of coordination with State developmental disabilities programs, and heavily child-oriented programs.

The Committee hopes that by establishing specific goals and by mandating their serving developmentally disabled adults as well as children, UAF's will be targeted toward the goals which this legislation is establishing for the State developmental disabilities programs. In the final analysis, the main goal is to get all available services and resources to the place where they are most needed—the developmentally disabled community itself. Major support in meeting this goal should be provided to the State Planning Councils by all UAF's.

The Committee is concerned that excessive decentralization within the Developmental Disabilities program is an obstacle to effective coordination and communication among the several HEW funding agencies which support the UAF program, and will continue to lead to problems in establishing a coherent national policy for the UAF program which is essential if the intent of this legislation is to be fulfilled. The Committee's intent is that the Office of Human Development take steps to ensure that the UAF support administered by the Developmental Disabilities program be administered by policy established and monitored at a national level, and that this support is coordinated with other Federal funding agency program support of the UAF network.

C. Renovation and Modernization

Six and a half million dollars are authorized to be appropriated for each of the fiscal years 1975, 1976, 1977, 1978, and 1979 for grants for renovation and modernization of UAF's or public or nonprofit facilities to be used for the establishment of satellite centers (see below). Priority shall be given to those applicants utilizing existing facilities. Such grants may be used only for facilities which, after renovation or modernization, comply with standards developed pursuant to the Architectural Barriers Act of 1968 (Pub.L. 90-480).

D. Satellite Centers

The University-Affiliated Facility-Satellite Center program proposed in this Act is a logical outgrowth of the University-Affiliated Facilities program initiated under Public Law 88-164 in 1963. That Act promoted the establishment of clinical training facilities designed to prepare professional personnel to work with mentally retarded persons. As previously stated, UAFs were primarily concerned with interdisciplinary professional training, although some clinical services were provided as a part of such training programs. During the past 10 years, the UAF's have turned out thousands of professional personnel specifically trained from an interdisciplinary point of view to work with developmentally disabled persons while at the same time developing new skills and expertise in the diagnosis and treatment of such individuals.

The UAF-Satellite Center program has been designed to promote the development of community-based clinical services so as to minimize costs while at the same time maintaining relationships with the rich base of expertise at the UAF's. UAF's are highly sophisticated centers staffed by experts in their respective fields, and the Committee believes that the proficiency of UAF personnel should be utilized to develop services in other areas, building upon local resources. The maintenance of a relationship between the UAF and Satellite Center is of utmost importance: since the satellite is primarily concerned with the delivery of clinical services, the UAF becomes the link to new knowledge and a source of continuing education and technical assistance.

This Act proposes the establishment of UAF Satellite Centers in States which do not have UAF's within their borders. Such Satellite Centers would work as back-up resources to other clinics within such States while themselves receiving back-up support from the UAF's. An intercommunicating network of UAF's, each working with a limited number of State Satellite Centers which in turn work with clinics throughout the States, could provide a communication and support system which would make the knowledge and skills found at any point in the country available to the smallest and most isolated clinic.

It is proposed that existing UAF's (as defined in this Act) would receive funds under this authorization to assist States in the development of such Satellite Centers. The initial phases of such development would be a joint needs assessment in conjunction with the Developmental Disabilities Planning Council of such State, to determine the best procedures for establishing a Satellite Center and to identify an appropriate agency or agencies to operate such a center.

The proposed legislation is designed so that a particular UAF will prepare a plan for the development of a satellite as prescribed in the law. The plan will contain provisions that will specify the types of training and services available for use by the State Planning Council and the target community. The UAF receiving funds to assist in the development of Satellite Centers will not commit or spend funds for such purpose without the express approval of the Developmental Disabilities Planning Councils in the States assisted.

A clinical facility designed to serve the developmentally disabled must involve a number of related and interacting professional disciplines. When fully developed, a Satellite Center should operate a fully comprehensive, interdisciplinary clinical program and serve approximately 250 to 300 new cases per year. Although each Satellite Center would be designed in accordance with State and local needs, one would normally expect to start with a core professional staff representing the fields of medicine, nursing, social work and psychology. Depending upon the availability of funds, the additional staff should be added from the fields of occupational and physical therapy, speech pathology, nutrition, dentistry, and psychiatry. Generally speaking, a professional with special education expertise is available to such clinical programs without being on the staff. If not, such a staff member would be added early in the development of the program. Consultants should be available representing the disciplines of neurology, opthalmology, eye, ear, nose and throat, orthopedics, and genetics. Laboratory facilities or resources should be available for routine laboratory work, EEG's amino acid studies, and chromosome studies.

It is hoped that Satellite Centers would be developed upon a base of existing services which would enable the Federal funds to be used for expansion rather than initiation of clinical service programs. However, if a State does not have an existing, nonprofit clinical service program within a service agency which is appropriate for expansion, then Federal funds may be used for the initiation of new programs. In some States, the most notable clinical service programs are attached to colleges or universities. It would be imprudent to expand such programs either directly or through subcontracts since the intent of this Act is to develop service-oriented clinical programs. It would be expected, however, that a UAF assisting in the development of a Satellite Center would take advantage of the expertise offered by a local institution of higher education and assist that institution, if requested, in the development of competencies and resources which would make it more useful to the Satellite.

The University Affiliated Facility which fosters the development of the Satellite Center would be responsible for (a) assisting the staffing of such a Satellite; (b) providing in-service training through workshops, seminars, and other means to the staff of such satellites;

and (c) assuring that back-up resources needed by the Satellite are available when needed.

As perceived by the Committee, the interaction between a UAF and a Satellite Center might be as follows: the UAF would receive planning funds to assist in the development of a Satellite Center in a State without a UAF. The staff of the UAF would meet with the State Planning Council to determine whether or not that Council wanted to develop such a Center in that State and, if so, what the procedures should be. A needs assessment study would be undertaken to determine the specific needs of the State for such a Center and the best possible location and agency. When the needs assessment was completed, the UAF would request and receive funds to initiate development of such a Center. Working with the selected agency and the State Planning Council, the UAF would assist in the selection of initial staffing and, if needed, initiate an inservice training program. As the Satellite Center developed, the UAF would subcontract funds to the selected agency to begin the provision of clinical services. Where local resources are inadequate for any given purpose, the UAF would be obligated to provide assistance. For example, if a geneticist were not available to consult with parents relative to unusual genetic conditions, the UAF staff would either provide or arrange for such services.

There may be situations where the UAF could not directly meet the needs of the State; in such cases, the UAF would be expected to seek appropriate skills or services, identifying where such skills or services might be found and arranging for them to become available to the Satellite Center. In other cases the Satellite Center might specifically request something different from that available at the original UAF. For example, if the Secretary of HEW designates that the UAF in Columbus, Ohio, shall contract with West Virginia for a Satellite, the West Virginia Satellite might find a particular treatment approach used in the Baltimore, Maryland UAF more appropriate and productive than one used in Columbus, Ohio. In such cases, it would be the responsibility of the Ohio UAF to secure the cooperation of the Baltimore Center and arrange for appropriate interactions.

No attempt has been made to define the regions or States to be served by the UAF's. This is partly because of the uneven distribution pattern of UAF's around the country. There are some HEW regions, for example, which have no UAF's, while others have more than one. The Committee leaves it to the Secretary of Health, Education, and Welfare, after consultation with the National Council on Services and Facilities for the Developmentally Disabled, to designate the States to be served by the UAF's. However, no attempt should be made to distribute funds and responsibilities in a way which satisfies university personnel while working to the detriment of the States. It is not necessary for every UAF to interact with Satellite Centers. A single UAF, properly geared up and funded to provided training and technical assistance can serve several States more efficiently than two poorly supported UAF's trying to serve one State each.

E. Applications

Applications for grants under Part A must contain reasonable assurances that: (1) the proposal is consistent with the appropriate State plan and that the applicant will provide the services and training required by the plan; (2) the facility will be associated with an institution of higher learning or a medical center; (3) all plans and specifications are in accord with regulations prescribed by the Secretary; (4) the title to the project is or will be vested in the State, or in one or more of the agencies or institutions making the application; (5) the non-Federal share of the funding for the renovation and modernization will be available upon completion of the project; (6) the facility will comply with standards of construction and equipment adopted pursuant to the Architectural Barriers Act of 1968 (Public Law 90-480) and with regulations of the Secretary concerning occupational health and safety standards; and (7) employees be paid wages commensurate with provisions of the Davis-Bacon Act, as amended.

A most important requirement for an application for a grant for modernization, for demonstration and training, and for satellite center establishment is the assurance that the proposal is consistent with the goals of the appropriate State plan. Applications can be approved by the Secretary only after they have been reviewed and commented on by the appropriate State Planning Council.

The Committee emphasizes again that the primary reason for the creation of the UAF's has been to serve persons with developmental disabilities through interdisciplinary training of professional personnel. Thus, the Committee feels that besides establishing the same basic goals for the States and for UAF's, the UAF and State Planning Council should interact. The UAF will submit its application to the State Planning Council for its review and comment before obtaining funds from the Secretary. If the Council agrees that the proposed UAF application is consistent in its goals and priorities with the State plan and the law, the application may then be sent to the Secretary for his approval. If the State Planning Council has questions or objections, it is expected that the Council and the UAF will discuss the matter and resolve their differences, at which time the plan or a revised plan could be agreed upon.

If, however, the State Planning Council fails to complete its review and comment within 30 days after submission of the application to the Council, the UAF may submit a request for approval directly to the Secretary. If the Secretary finds that the delay by the Council has been arbitrary, capricious, or unwarranted, he may approve the application himself, without any further action by the Council. In a case where the findings of the Secretary do not meet this criteria, he shall return the application to the State Planning Council for action.

It is the Committee's intention that the Councils and the UAF's will work together in a partnership, pooling their talent and resources for the benefit of persons with developmental disabilities. The goals that are set forth in the State plans are to be consistent with the goals established for UAF's. The Committee anticipates that this requirement for mutual consistency will form the basis for cooperation among those elements planning and providing the necessary resources for service, to developmentally disabled individuals in the community. The ultimate goal is to get the appropriate needed services to the severely handicapped individual who is the focus of this program.

III. FORMULA GRANTS TO THE STATES (PART B)

A. Authorizations, Formula, and Allotments

Section III, for the purpose of making formula grants to the States for planning, provision of services, and construction and operation of facilities for persons with developmental disabilities, authorizes appropriations of $50 million for FY 1975; $85 million for FY 1976; $95 million for FY 1977; $100 million for FY 1978; and $110 million for FY 1979. It is the Committee's belief that increased authorization and appropriation levels are necessary so that the States may meet the increased responsibilities mandated by this Act.

The authorizations are to be allotted among the States on the basis of (1) population; (2) extent of need for services and facilities; and (3) financial need. The minimum allotment for a State shall be $200,000; the minimum allotment for a territory shall be $50,000. No State shall receive less than it did in FY 1974. In determining the extent of need for services and facilities, the Secretary shall take into account the scope and extent of services specified in a State's plan.

Any funds unobligated by a State by the end of the fiscal year shall be available for reallotment by the Secretary. However, that part of a State's allotment for a fiscal year which is designated by it for construction, renovation or modernization may remain available for an additional fiscal year even if unobligated the first year. In addition, if more than one State agency is charged with the administration or supervision of designated portions of the State plan, the State may apportion its allotment among such agencies in a manner commensurate with the respective agencies' responsibilities. If there should be a cooperative effort between two or more States, or between agencies in two or more States, Federal funds allotted to the States may be combined.

B. Administration of Grants

The Secretary of Health, Education, and Welfare is required by subsection (f) of section 112 to administer the grant program authorized under Part B in accordance with uniform Department of Health, Education, and Welfare policy. There is a document, Circular A102 from the Office of Management and Budget, which provides guidelines for DHEW grant and contract procedures; in other words, OMB Circular A102 establishes uniform procedures for the entire Department in issuing grants and contracts, including in-kind match requirements and personnel utilization. The provisions of this Circular are applied throughout all HEW programs except for the administration of formula grants under the 1970 Developmental Disabilities Act. This exception has hindered the granting of contracts for developmental disabilities projects. The Committee emphatically stresses its intention that the Secretary administer all programs in accordance with the procedures set forth in OMB Circular A102.

C. Grants of National Significance

Of the sums appropriated pursuant to Part B, section 111, not more than 10% will be available to the Secretary for grants of national significance. These grants may be made to States, public or nonprofit private agencies and may be awarded only after consultation with the National Council on Services and Facilities for the Developmentally Disabled (a new provision reflecting the Committee's view that the expertise on the National Council should be effectively utilized by the Secretary). Priorities for these grants include integrated service model projects, demonstration projects to coordinate and utilize all available community resources, and public education projects.

The Committee feels that there is a lack of public awareness of the persisting life problems of the developmentally disabled individual. This problem is of sufficient national significance to warrant a project of public understanding which would alert the American people to the plight of these individuals. Documentary evidence of the status of developmentally disabled people and the potential for a more humane life should be the major focus of this project. The organization and production of films, radio programs, television, conferences and/or written material should be of the highest professional quality. The project should not become a fragmented public relations campaign which serves as propaganda for the sponsoring agency. It should interlock and coordinate with projects of public understanding which may be initiated at the State level as well as with other national programs of public awareness. Evidence of scientific and technological knowledge about these individuals should be included where appropriate.

D. National Council on Services and Facilities for the Developmentally Disabled

The National Council authorized by section 113 is a reorganization of the present National Advisory Council on Services and Facilities for the Developmentally Disabled. Under present law, the Council advises the Secretary but is administered by the Office of Human Development.

The Committee has found that at times recommendations of the Council have not reached the Secretary nor has there been a significant consideration of the Council's recommendations in the development of the developmental disabilities program. Thus, the Committee has placed the Council directly in the Office of the Secretary, and provides $100,000 for each of the five fiscal years in the bill for its operation. The Secretary shall make available to the Council such staff and data as it may need.

The Council's membership is increased from twenty to twenty-five. Sixteen of these 25 members shall be advocates in the fields of service to persons with developmental disabilities and shall consist of leaders in State or local government, in institutions of higher education, and in advocacy organizations. Five of the sixteen shall be representatives of State or local public or nonprofit private agencies responsible for services to the developmentally disabled population, and five others shall be consumers or parents or guardians of consumers. A consumer (i.e. a person who is receiving services or has received them at some time in the past) shall be replaced by a parent or guardian only if he is so severely disabled that he is unable to represent himself. In order to promote and facilitate coordination and cooperation among the agencies of DHEW, the Committee has mandated that the Deputy Commissioner of the Bureau of Education for the Handicapped, the Commissioner of the Rehabilitation Services Administration, the

Administrator of the Social and Rehabilitation Service, the Director of the National Institute of Neurological Disease and Stroke, the Director of the National Institute of Mental Health, and three other representatives of the Department of Health, Education, and Welfare serve on the National Council. Each member shall serve a term of four years. A member of the Council whose term has not expired by July 1, 1974, shall continue to serve his term until the date his term would have expired had the 1970 Act remained in effect. No member shall be reappointed until he has been off the Council for one year.

The duties of the National Council have increased. Besides advising the Secretary with respect to the promulgation of regulations developed pursuant to enactment and studying and evaluating the authorized programs, the National Council is to (1) study and evaluate programs authorized by this title to determine their effectiveness; (2) monitor the development and execution of title I and report directly to the Secretary concerning any delay; (3) review and advise the Secretary with respect to grants of national significance; (4) review the grants and contracts entered into with respect to the evaluation system established in section 118; and (5) submit annually to the Congress an evaluation of the efficiency of the administration of title I of S. 3378.

E. State Planning Councils

In addition to reorganizing and strengthening the National Council, the Committee has also changed and enlarged the functions of the State Councils. The bill as reported provides for the appointment of the State Planning Council by the Governor, as Chief Executive Officer of the State. Designation of the Governor as the appointing official is intended to ensure that the Council will have sufficient stature in the State administrative structure to provide the monitoring and evaluation of the programs instituted by the State plan and to ensure the coordination of programs affecting individuals with developmental disabilities administered by the various State agencies. The Committee does not intend to exclude the appointment of members of the council by the State legislature in those States where such a procedure is established. In such cases, this procedure would be permissible, as long as the intent of the reported bill to place the Council in an administrative position above that of State agencies providing services for individuals with developmental disabilities is preserved, and the membership of the Council adheres to the composition specified in section 115 (d) of the reported bill. This membership shall include representatives of the principal State agencies, local agencies and non-governmental agencies and groups concerned with services to persons with developmental disabilities. One-third must consist of consumers or their parents or guardians. Each State is responsible for the assignment of adequate personnel to insure that the Council may carry out it duties.

The duties of the State Planning Councils are to (1) develop and prepare the required State plan; (2) approve, monitor, and evaluate the implementation of the State plan and submit to the Governor and State legislature an annual report on this implementation; (3) establish priorities for the distribution of funds within the State; (4) review and comment on all State plans in the State which concern persons with developmental disabilities; and (5) submit to the Secretary, through the Governor, any periodic reports which the Secretary may reasonably request. The State Council shall also approve the design for implementation of its State plan which is submitted by the administering State agency and shall have access to all other State plans relating to persons with developmental disabilities.

In evaluating and reviewing the State plans, State Planning Councils are expected to utilize all available communication with, and input from the community, including but not limited to public hearings and other public meetings as well as other media forms.

F. State Plans: Priorities and Goals

The State plans, which are drawn up by each individual State Planning Council, must contain the following priorities and goals: (1) to reduce and eventually eliminate inappropriate institutional placement of persons with developmental disabilities; (2) to improve the quality of care, habilitation and rehabilitation of persons with developmental disabilities for whom institutional care is appropriate; (3) to provide early screening, diagnosis, and evaluation of developmentally disabled infants and preschool children (including maternal care developmental screening, home care, infant and preschool stimulation programs and parent counseling and training); (4) to provide counseling, client program coordination, follow-along services, protective services, and personal advocacy on behalf of developmentally disabled adults; (5) to support the establishment of community programs as alternatives to institutionalization, designed to provide services for the care and habilitation of persons with developmental disabilities, which programs utilize the resources and personnel in related community programs; (6) to protect the human rights of all persons with developmental disabilities; and (7) to provide for interdisciplinary intervention and training programs for multihandicapped individuals.

The Committee believes that these goals reflect its high priorities on prevention and early treatment, development and maximum utilization of community resources and alternatives to institutionalization, and humane and effective care whenever institutionalization is absolutely necessary. It is the Committee's feeling that planning for these goals must begin immediately.

There has been a growing realization over the past decade that the institutional placement of individuals with developmental disabilities is sometimes inappropriate to the full development of their maximum level of ability as members of our society. This has been reflected in the efforts which several States have made to develop alternative programs to State institutions. In the transition to community programs, greater responsibility is placed upon local governments to coordinate the several community programs which are called upon to serve persons with developmental disabilities, such as medical services, social services, educational services, legal and protective services, and specialized services (transportation, information and referral, counseling).

The Committee realizes that special assistance and planning will be needed in the communities for these services to be made available to the degree needed in order to carry out the purpose of this Act—to improve the provision of services to persons with developmental disabilities. The requirements of the State plan make very clear the importance of coordinating existing services and planning for new community services to prevent the occurrence of developmental disabilities insofar as possible, to provide early diagnosis, treatment and evaluation when the conditions are present, and finally to serve fully and adequately those persons who suffer from developmental disabilities.

The State plan is specifically required to provide for the maximum utilization of all available community resources including volunteers serving under the Domestic Volunteer Service Act of 1973 (Pub. L. 93–113). That Act provides for support of the training of citizens of all ages in volunteer services to the community, including specifically services for individuals with developmental disabilities, especially those with severe handicaps. The Committee urges the States to build upon this related Federally supported program. The involvment of retired senior volunteers and of foster grandparents seems particularly valuable, after appropriate training has been provided them, as individual patient advocates assigned to an individual with one or more developmental disabilities. In such a role, the volunteer can provide necessary support to that individual in his effort to function independently in the community. Other voluntary groups such as service organizations should also be encouraged to devote some emphasis to programs which can increase the availability of services or otherwise aid individuals with developmental disabilities.

G. State Plan: Content

The State Planning Council develops the State plan; it must contain the following:

In the area of administration and staffing: (1) the designation of the State agency or agencies which shall administer and supervise the administration of the State plan (or a particular portion of the plan) and the designation of a State agency to supervise the administration of construction, modernization or renovation grants; (2) a description of the methods of administration to be used in implementing the plan (including personnel standards, selection and advancement); (3) an assurance of adequate personnel for the State Planning Council; (4) a provision that personnel assigned to the State Planning Council shall be solely responsible to such Council; (5) a requirement for adequate record and report keeping and adequate access to such materials by the Secretary; (6) provision for adequate fiscal control and fund accounting procedures; (7) an opportunity, to the maximum extent feasible, for prior review and comment by the State Planning Council on all State plans in the State affecting developmentally disabled persons; (8) a provision that all relevant information concerning any programs affecting persons with developmental disabilities shall be made available to the Planning Council; (9) the availability of any other information which the Secretary may require, and (10) a provision for fair and equitable arrangements (i.e. preservation of rights and benefits, maximum efforts to assure employment, and training and retraining) of employees who, as a result of deinstitutionalization, may lose their jobs or be transferred. This latter provision should not change the priority for deinstitutionalization, the elimination of inappropriate institutional placement, or the Committee's intent that any decisions on service sites or modes of care be made on the basis of the best care and treatment appropriate to the developmentally disabled persons.

In the area of utilization of funds and resources: (1) a description of the quality, extent and scope of services already being provided in the State which meet the goals specified in section 114(a) of this legislation; (2) a description of the quality, extent and scope of services being provided in that State under other Federally assisted programs which serve persons with developmental disabilities and a description of how funds allotted to the State under this Act will complement and augment these services; (3) an explanation of the policies and procedures for the expenditure of funds allotted to the States pursuant to this Act; (4) assurances to the Secretary that the funds received by the State will be used to make a significant contribution toward strengthening services for individuals with developmental disabilities; that part of the funds may be used by public or nonprofit private agencies, institutions and organizations; that funds will be used to increase and supplement funds already being directed toward the goals of the State plan, not supplant other funds; and that there will be reasonable State financial participation in carrying out the cost of the State plan; (5) a provision for special financial and technical assistance for urban and rural poverty areas; (6) a provision for the maximum utilization of all available community resources (including volunteers serving under the Domestic Volunteer Service Act of 1973 (Pub. L. 93-113) and other appropriate voluntary organizations); and (7) a provision that services and facilities under the plan will conform to standards prescribed in regulations developed pursuant to title II of this Act.

In the area of evaluation: (1) a requirement for an annual review and evaluation of the State plan by the State Planning Council; (2) a description of the methods to be used in evaluating the effectiveness and accomplishments of the State in meeting the needs of developmentally disabled persons; and (3) provision, within 36 months after the date of enactment of this legislation, for the implementation of an evaluation system compatible with the model evaluation system developed pursuant to section 118 of this measure.

In the area of construction, renovation and modernization: (1) a specification (not to exceed 10% of the State's allotment) of the percentage (and maximum amount) of the State's allotment under Part B which may be devoted to construction, modernization or renovation; (2) an inventory of existing facilities, relative need, and priority items if Federal funds are to be allotted for construction, modernization and renovation (which must be done in compliance with standards prescribed pursuant to the Architectural Barriers Act of 1968); (3) provision for a hearing for every applicant for a construction, modernization or renovation project; and (4) reasonable assurance that adequate financial support will be available to complete construction of, maintain and operate any facility assisted by Federal funds.

H. State Plan: Relationship of State Planning Council and State Agency responsible for administration of State plan

The study conducted by the Comptroller General of the United States on the developmental disabilities program brought to the Committee's attention that in the case of most States, the planning function—which the Congress had originally intended to be the primary duty of the State Planning Councils—had been neglected and priority had been given to the grant disbursing function which the Councils were also performing.

In addition, the GAO study pointed out that the Congressional intent for the program was not being met by the present system established under the Act, and that monies did not necessarily perform the gap-filling function. For instance, in the nation as a whole, less than 5% of developmental disabilities funds were spent on any comprehensive planning or needs-assessment studies to determine better utilization of resources to assist developmentally disabled persons.

Faced with the GAO study, the Committee has tried to develop a system by which the State Planning Councils can devote their time to planning for the needs of the developmental disabilities community; this planning should take in the entire spectrum of relevant State and Federal programs. The burden of day-to-day administration of grants should not lie with the Council, but with the State agency or agencies responsible for the expenditure of funds in accordance with a design for implementation which has been approved by the State Planning Council.

The Committee, therefore, has designed a system which provides for cooperation and complementary functions between the State Planning Council and the State agency which administers the program. The State Planning Council is to act in a leadership and advocacy role: to be responsible for the State plan, for the general direction and goals of the program, for the identification of gaps and of needs, and to provide the uniform planning authority that is needed for the maximum effective utilization of the available resources.

The State agency is to administer the funds through the design for implementation which is to be part of the State plan. The design for implementation is a document prepared by the State agency and is that part of the State plan which includes details on the priorities for spending, for the use of funds provided under this Act, on the specific objectives to be achieved, on the methods of implementation, on a method for periodic evaluation of a program's effectiveness in meeting State plan objectives, and also includes a list of programs and resources to be utilized.

Neither the State Planning Council nor the implementing State agency alone can do the job. While the Council has the prime responsibility for the development and updating of the comprehensive State plan, the agency has the equally critical responsibility to select from alternative strategies those best methods of actually implementing the plan through its program development and program evaluation procedures. The Committee stresses that bringing needed services to persons with developmental disabilities can occur only if this partnership succeeds.

1. Special Projects

Section 119(a) authorizes appropriation of $17,500,000 for FY 1975; $20,000,000 for FY 1976; $22,500,000 for FY 1977; $25,000,000 for FY 1978; and $27,500,000 for FY 1979 for grants for special projects and demonstrations which hold promise of expanding or otherwise improving services to persons with developmental disabilities (especially persons who are also disadvantaged or multihandicapped). The projects and demonstrations shall include parent counseling and training, early screening and intervention, infant and preschool programs, seizure control system, legal advocacy, community-based counseling, care and housing, and other necessary services. The special projects are to be reviewed and commented on by the State Planning Council.

This special project authority has not previously existed in the Developmental Disabilities Services and Facilities Construction Act. Historically, monies for these purposes have been pieced together from portions of several widely varying pieces of legislation, each Act designating clearly its parameters of kind of service, to whom, and for what purpose. These Acts have included authorities for mental retardation planning and implementation; Comprehensive Health Planning (Section 314(e) of the Public Health Service Act); MR Community Facilities-Initial Staffing; section 4(a)(1) of the old Vocational Rehabilitation Act (section 304(b)(1) of the Rehabilitation Act of 1973).

As the Committee has noted in the report on S. 3108, the Rehabilitation Act Amendments of 1974 (S. Rept. 93–1139), the appropriateness of funding special projects for developmentally disabled persons under the Rehabilitation Act authority was carefully evaluated during review of this legislation in 1973, especially the question of whether such projects should be funded if such individuals do not otherwise meet the requirements for eligibility for vocational rehabilitation services. As a result of this review and evaluation, the Committee decided to create specific authority under the Developmental Disabilities legislation.

The Committee's intent is to provide as smooth as possible transition in transferring the authority for providing such funding, and notes that the difficulties experienced by such projects since the enactment of the Rehabilitation Act of 1973 is unnecessary. In effecting this transition the Department should follow the following guidelines: (1) current and continuation projects for the developmentally disabled persons funded under the Vocational Rehabilitation Act or the Rehabilitation Act of 1973 should be continued until the new authority in the Developmental Disabilities legislation is authorized; (2) developmentally disabled individuals who are receiving services under such projects should continue to be eligible for them, and special projects serving such individuals should continue to be funded; and (3) funding for projects for individuals with developmental disabilities should be continued under the Rehabilitation authority even after the enactment of Developmental Disabilities legislation consistent with the intent of Congress that no individual is to be refused service under the Rehabilitation Act unless it is demonstrated beyond any reasonable doubt that such individual is not then capable of achieving a vocational goal.

Thus the Committee wishes to make very clear that it will not accept the interpretation that after the enactment of special project authority under this legislation all special projects which serve developmentally disabled persons must be funded under the Developmental Disabilities legislation, or that developmentally disabled persons are no longer eligible under the basic State grant program in the Rehabilitation Act. Individuals with developmental disabilities shall still continue to be eligible as all other handicapped individuals are eligible under the Rehabilitation Act, either under special projects or the basic State grant program.

The Committee further takes note that $12.5 million has been appropriated in FY 1975 for these special projects for the developmentally disabled, and expects that this funding level will at least be maintained for such projects under the new special project grant authority in this legislation. The Committee bill includes language providing that special projects, or components of special projects funded under this legislation, shall not be eligible for funding under the special project authority in the Rehabilitation Act. This language has been included to assure that this new authority is utilized and to make clear the different goals and thrusts of the two laws.

In the years prior to the Developmental Disabilities Act, there were only these assorted specific authorities with limited funding available to initiate services throughout the nation. Out of this approach came the design of central office authority for decisions and a national priority system based not necessarily on the most pressing needs of localities but on the allowable services under the available Acts.

The challenge has been to interpret authorities as broadly as possible to allow flexibility and as much responsiveness to needs in the field as possible. The needs were so wide and deep that almost any authority spoke to some great need in the field, but not necessarily the top priority need; nor were the services designed to fit together in any coordinated way with any one State authority to monitor needs or services.

The Committee believes that special projects must not be used to provide additional funds to fill local service needs. This authority will be utilized fully for putting in place regional and national activities which either design new means for attacking regional problems or national barriers or constraints to full programming for the substantially handicapped. Of major importance is the design of programs for multi-handicapped individuals. For example, there are no models of programs for the mentally retarded deaf person or the cerebral palsied blind person which can be replicated in areas where services are available to these persons. The Committee feels strongly that the highest priority must be given to those projects which demonstrate that this need will be met.

Finally, special projects must serve as role models for State or local agencies. The innovative projects must devise means for solving problems encountered nationwide. Other projects may set up systems to attack specific barriers to goals.

K. *Evaluation*

Evaluation as discussed in this report has several distinguishing characteristics relating to focus, methodology and functions. The following operational description clarifies these characteristics:

> Evaluation (1) assesses the effectiveness of an ongoing program in achieving its objectives, (2) relies on the principles of research design to distinguish a program's effects from those of other forces working in a situation, and (3) aims at program improvement through a modification of current operations.

Provisions of S. 462 with respect to evaluation of programs for the developmentally disabled are primarily directed to two issues. First, to the extent that the States are chiefly responsible for determining the needs for service, establishing program priorities and developing strategies for successful implementation of the program, the Committee reached the conclusion that the States must also bear the principal responsibility for evaluating services rendered to the developmentally disabled. Many of the State plan provisions have been designed to strengthen the capabilities of State councils in order to fulfill their planning and evaluation responsibilities, to facilitate their efforts to do so and to give them a clear mandate to carry out these functions. Comprehensive planning for future needs must begin with an accurate assessment of existing services and resources.

Second, evaluation of human service programs has in too many instances degenerated into a numbers racket wherein numbers served has become criterion of success rather than benefits gained by those persons served.

Section 118 unequivocally defines the Committee's intent as to the scope and focus of the evaluation requirements for programs provided for the developmentally disabled. In specifying Federal development of a model which can be adopted by each of the States, the Committee has attempted to strike an appropriate balance between the need for uniform evaluative criteria, standardized definitions and methodology, yet recognize the differences among States as to their organization for human services and the need for flexibility in implementation.

Another consideration taken into account by the Committee was the anticipated costs involved in the design of such a complex comprehensive system. The development of a model system is seen as an efficient cost effective approach which should provide for improved quality and desired uniformity, which could not be achieved by each State undertaking the initial development of such systems.

The Committee recognizes that the investment costs associated with the initial design, development and implementation of such systems are extraordinary and exceed the amounts available for such purposes in the program appropriation. The Committee therefore authorizes $1,000,000 to be appropriated in each of the first two successive fiscal years of enactment to meet this need. However, it is the express intent of this Committee that the annual operating expenses, the costs of system maintenance and subsequent modification of such evaluation systems in the various States should be funded under the formula grant appropriations.

The design and development of a model of evaluation and comprehensive data system is a desirable step forward. Prudent investment in the research and development of such a model could improve evaluation efforts across many programs in government.

An issue of concern to this Committee is the Federal role and responsibility for overall evaluation of the Developmental Disabilities program. The Secretary, the National Advisory Council, the State Developmental Disabilities Planning Councils, and the Congress each have designated responsibilities for carrying out these provisions. One step which has been taken by the Committee is to provide increased Congressional oversight in this area by requiring that the model evaluation system developed under Section 118 be transmitted to the appropriate Congressional Committees for review. Further, the role and responsibility of the National Council in evaluation has been substantially increased and more clearly defined.

It is anticipated that many of the administrative difficulties which have beset developmental disabilities programs will be alleviated by the establishment of the Office of Developmental Disabilities in the Office of the Secretary. This should be of benefit to evaluation planning as well as other related administrative processes. It is the Committee's judgment, however, that in order to best meet the new evaluation objectives of this legislation, to meet existing requirements, and to overcome past deficiencies, responsibilities for Federal evaluation activities should be fully integrated in a single designated staff unit.

This unit is to be established in the Office of Developmental Disabilities for the purpose of: (1) developing a unified conceptual framework for overall evaluation of the developmental disabilities program; (2) planning, designing and providing for the implementation and control of evaluation projects within this framework; (3) consulting with and coordinating related activities of all agencies and organizations necessarily concerned with Federal level developmental disabilities evaluation.

In carrying out these and other related tasks, this unit will provide technical staff support for evaluation to the National Council, the Division of Developmental Disabilities and the Office of the Handicapped. For this purpose the Secretary shall make available adequate technical staff and clerical support.

Finally, the Committee expects that answers to four major questions must be found through the evaluation program and information system:

(1) Who is being served, who is providing the service, how is the program being carried out?

(2) Are programs and/or projects pursuing appropriate objectives or goals?

(3) Do the programs and projects achieve or lead to beneficial results to the consumer?

(4) Which of the available program alternatives is most effective and efficient?

Model State Evaluation System

In considering changes to the Developmental Disabilities legislation and reviewing the efforts of the States to provide comprehensive planning for services to individuals with developmental disabilities, the Committee became concerned about the lack of adequate methods to evaluate services and service systems in a way which truly reflects the impact of such services in meeting the needs of developmentally disabled persons, and assesses the impact of such services on the developmental progress made by an individual in the ability to perform more complicated tasks and to develop the skills to live in a more normalized environment in society. The Committee believes that many evaluation methods that presently exist may, in fact, do an exemplary job of evaluating services, or even the adequacy of services, but few methods actually evaluate the effect of individual services upon a developmentally disabled person, or provide a benchmark for an agency to judge how its services are actually impacting on the development of an individual.

The Committee is aware of the development, however, of new evaluation systems which show great promise of being able to accomplish such goals. Such systems, based on individual data, are being utilized in several States, (Nebraska, Florida, Ohio and others) and may represent a great breakthrough in the evaluation of the effectiveness of services for severely disabled individuals. Believing that the development of such a system, or several systems, could be very useful to States, and to the Congress, in the assessment of the impact of human service programs, the Committee has directed the Secretary to develop by February 1, 1977, a design for a comprehensive system for the evaluation of services provided to persons with developmental disabilities and a time-phased plan for the implementation by the States. This time-phased plan will specify a minimal evaluation system to be implemented by all States by October 1, 1977, leading to the establishment of the comprehensive evaluation system within 36 months after the date of enactment of this Act. The intent is to assist the States in the development of similar systems by which they may judge all services developed for and delivered to individuals with developmental disabilities.

The keystone of this system should be clear: the Congress has directed the Secretary to develop specific criteria by which the developmental progress of a person with developmental disabilities may be measured. Such criteria shall be designed to be utilized by agencies and facilities to evaluate the effectiveness of services provided to an individual. For this reason, the Committee wishes such a system to be designed to utilize information and data which may be developed by individualized written habilitation programs (as required under Part B of title II, and other comparable individualized data) to provide guidelines for the alternative services including the costs of such services and the benefits such services represent for an individual.

It is the Committee's intent that the end result of the development of such a system shall be criteria on which to base the evaluation of the performance of an agency in delivering services to an individual, and that such criteria shall measure that performance of an agency on the basis of the progress made by an individual in mastering complicated tasks and developing the ability to live more normally in society.

The Committee also recognizes that the development of such criteria is not an easy task, and that an evaluation system based on such criteria must be flexible and open to change as experience and new knowledge dictate. However, the establishment of such criteria is integral to any progress this Nation may make in assuring the rights and providing necessary services to individuals with developmental disabilities, and an evaluation system based on such criteria must be developed.

IV. FEDERAL ADMINISTRATION OF PROGRAM

A. Regulations

The Committee directs the Secretary of the Department of Health, Education, and Welfare, not later than 90 days after the enactment of this legislation, to promulgate final regulations. The Committee believes that the eight months the Department took to promulgate regulations on the Rehabilitation Act of 1973 was an unreasonable length of time and gave the impression of reluctance on the part of the Department to actually implement the intent of the Congress. The Committee emphasizes its concern over this matter and thus requires the Secretary to move more quickly in writing regulations for this Act.

There is a provision for a waiver of the regulations if the Secretary decides that the regulations would impede the implementation of a project which is consistent with the goals of this legislation. Any waivers must be issued on a case-by-case basis and only for a specific period of time, not to exceed 36 months. The Secretary must publish in the *Federal Register* the fact that an application for a waiver has been submitted by a State and cannot approve or disapprove the application less than 60 or more than 90 days after the date of publication. In addition, the waivers must be reviewed annually and the Secretary shall submit his justification for any renewal to the appropriate committees of Congress.

B. Audit

Each recipient of a grant or contract must keep such records as the Secretary prescribes so that the Secretary and Comptroller General of the United States shall have access to any books, documents, papers and records which are pertinent to the grant or contract.

C. Advance Funding

Section 4 authorizes that appropriations under this Act shall be included in the appropriations act for the fiscal year preceding the fiscal year for which they are available for obligation. It is the Committee's policy to provide such funding so that States may plan in advance of the fiscal year.

D. Payments and Federal Share

The Secretary shall make payments to the States from time to time in advance on the basis of estimates of the sums the State will expend under the State plan; these payments shall cover the Federal share of expenditures. The Federal share with respect to assistance under Parts A and B may not exceed 70%, with the following exceptions: (1) the Federal share for projects of national significance and services to a poverty area under Part B may not exceed 90% of the necessary cost; (2) the Federal government will pay part or all of the cost of special projects.

E. Withholding Payments

The Secretary, after reasonable notice and opportunity for a hearing to a State Planning Council and State agency, may withold payments whenever he finds that the Council or State agency is not in compliance with the provisions of the State plan or the regulations of the Secretary.

F. Employment

The Committee bill includes a provision (section 5) which requires the Secretary of HEW to insure that recipients of assistance under this Act take affirmative action to hire and advance in employment handicapped individuals.

The 1973 Rehabilitation Act includes several provisions which directly and indirectly promote the employment of persons with handicaps.

Section 501 of the Act requires each Federal department, agency, and instrumentality to take such affirmative action, including the submission of affirmative action plans for approval by the Civil Service Commission, which is to monitor and review, with the Federal Interagency Committee on Handicapped Employees, the implementation of such plans.

Section 503 of the Act requires Federal contractors and subcontractors to take affirmative action to hire, place, and advance handicapped employees.

Section 504 of the Act prohibits discrimination against qualified handicapped individuals in participation in, or acquiring of benefits under, any program or activity receiving Federal financial assistance.

Section 5 of the Committee bill, then, is designed to conform programs and activities undertaken in conjunction with this developmental disabilities legislation to those under the Rehabilitation Act, to the extent that they relate to taking affirmative action to hire, place, and advance in employment, handicapped individuals.

It is the responsibility of the Secretary to monitor the affirmative action programs of recipients of assistance under this legislation. In this connection, the Committee expects the Secretary to require such recipients to file with him their affirmative action plans. Further, he must monitor the activities of such recipients in order to assure the full implementation of this provision in accordance with the intent of the Committee. Finally, the Secretary will report annually to the respective committees of Congress on the progress being made under these plans and their implementation.

V. REPEAL OF EXISTING LAW

Parts B and C of the Developmental Disabilities Services and Facilities Construction Act are repealed 90 days after enactment of this Act.

TITLE II

VI. FORCES BEHIND INSTITUTIONALIZATION AND DEINSTITUTIONALIZATION

A. History of Attitudes Towards Retardation

Attitudes towards retarded individuals—both by the public and by professionals—have gone through many changes during the history of mankind. Retardation is a condition that has been known since the days of antiquity and has always evoked strong responses—of one kind or another—from the general public. Historically many cultures dealt with this social problem in a clearcut and vigorous manner. For example, the Spartans cast obviously defective children into the river to perish. For many, many centuries the feeble-minded were treated harshly, were shunned, ostracized and neglected.

It is not until the middle of the 19th century that serious and scholarly approaches were applied to the problem of mental deficiency. For example, in 1846 Edouard Sequin published "The Moral Treatment, Hygiene and Education of Idiots and Other Backward Children." This work has been recognized as a classic in the field of mental retardation. In the same year the first State legislation in the U.S. for the establishment of an institution for the retarded was introduced in the New York State legislature. The legislation was not enacted but the first such institution was established in 1848 in Massachusetts. Subsequently, Sequin came to the United States and played a major role in initiating public care for the mentally retarded in the U.S.

1850–1875, The Hope for Curing Retardation. The first institutions in the U.S. for the retarded had as their goal the complete rehabilitation of retarded persons, with the objective of successful integration into community life. These institutions were primarily designed to be institutional. However, before long it was realized that with techniques available at those times, few of the mentally retarded could be successfully returned to the community.

1875–1900, The Need for Custodial Care. By the third quarter of the 19th century, there had been a gradual shift from the goal of cure to that of maximum improvement. The same tools from a training standpoint were put to use but the objective now was to equip the mentally retarded so they could maintain the institution and defray the cost of its upkeep.

1900–1910. The Period of Eugenic Alarm. While the 19th century had opened with a recognition of the existence of the problem of the mentally retarded, the 20th century opened with a condemnation. Increasingly, mentally retarded were viewed as antisocial, as burdens upon the society, and as persons who married young and had many children they could not support. Thus it was that efforts to prevent retarded persons from reproducing became one of the chief objectives of the modern eugenic movement about the turn of the century.

1910–1925, The Period of Social Advance. Together with the concern about eugenics there was a very broad increase in the exploration of mental deficiency. Many official and non-official groups were set up to study what could be done. Often, however, emphasis continued to be placed on eugenic approaches of one sort or another. Particularly stressed were life segregation (or at least segregation during the reproductive period) and sterilization.

1925—present time: Period of Movement Towards Community Care. It is now almost 50 years since experts in the field of mental retardation first began to talk about alternatives to large institutions. Unfortunately, progress in developing these community alternatives continues to be slow and—as this Committee repeatedly heard in dramatic testimony from witnesses—the care provided in institutions almost always still leaves much to be desired. There remains disagreement on what the proper nature of community care or community supervision should be, and even where there is agreement, speed has been lacking in developing such programs at the local level.

B. Models of Mental Retardation

Developmentally disabled persons for too long have been cast into a number of destructive models which have been used as justification for their rejection and exclusion from the mainstream of society. Some of these models are still prevalent today. They include the view that developmentally disabled persons are sub-human organisms; that they are lacking in many of the needs, aspirations and sensitivities of other human beings. From this it follows that the human and legal rights of the developmentally disabled can be curtailed and ignored. In many ways they are allowed minimal freedom and managed more or less as animals. In addition, developmentally disabled persons are often viewed as a threat to society. Thus, it is concluded they must be isolated from the larger society. In this sense society is seen as needing protection from them, and it is to provide this protection that prison-like institutions have been considered necessary.

A further rejecting model, which often is only a thinly veiled form of dehumanization, is that the developmentally disabled are seen as the object of pity. They are viewed as "suffering" and therefore requiring loving nurture and protection. Here the emphasis is placed on keeping developmentally disabled persons contented but the result is treatment without human respect or dignity. Related to this model is the view of developmentally disabled persons as "eternal children."

Finally, there is the view that developmentally disabled individuals are "diseased." They are viewed as sick and in need of constant care. This leads to indefinite custodial care. This last model is gradually being replaced by a developmental view of mental retardation. Such a view stresses that all developmentally disabled individuals have potential for learning and growth.

From this developmental model, it follows that custodial care—which is predicated on the assumption that certain individuals are essentially incapable of development—must be rejected. The newer developmental model emphasizes concrete program goals for individuals and therefore encourages evaluation based on specific outcomes.

A final, but critically important dimension of this new model is that developmentally disabled persons should live like nondevelopmentally disabled persons to the greatest degree possible. Every effort should be made to assist developmentally disabled persons to maximize their ability for self-care and to live normal lives. From this, it also follows that each developmentally disabled person should be allowed to live in the least restrictive environment conducive to his or her maximum development.

C. Conditions in Institutions

Despite the wide acceptance of newer models of conceptualization regarding mental retardation, testimony before this Committee exposed overwhelmingly that totally unacceptable conditions still prevail in many public and other facilities for the developmentally disabled. Many of the institutions can best be described as "hopeless places" dedicated to custodial care of lifelong residents. All too often these institutions are far removed from urban areas and represent an effort of society to forget its obligation to the residents. Frequently they have little or no outreach and are unconnected with the existing community facilities. They generally lack any commitment to change and have not accepted the developmental model described above. Frequently large proportions of staff will feel that the residents really "cannot be helped."

In addition, all too often State legislatures have not adequately funded these institutions; often relying very heavily on uncompensated (and perhaps unconstitutional) resident labor performed by the developmentally disabled themselves. Frequently, too, the professional and nonprofessional staff of these facilities do their routine and often dreary work without approval from peers or any part of the public.

All these circumstances tend to generate environments in which residents can be neglected and even abused, and which unfortunately often lead to deterioration of the residents' physical and mental condition. The enactment of minimum standards itself will not solve these problems but it can be a significant catalyst in bringing about urgently needed changes.

In testimony before this Committee the United Cerebral Palsy Association, Inc., in its presentation, stated as follows:

> (We) deplore the disgraceful conditions still in existence in the back wards of some of our large institutions. We are particularly concerned because many of the residents of these back wards are victims of cerebral palsy. Most of them have never known a day of therapy or education in their institutional lives. Many of them came from homes where they were functioning, before they were institutionalized, at much higher levels and where they were more independent in the activities of daily living—feeding, dressing, and toileting. Some of them at one time, as a result of many hours of therapy, much effort and expenditure of many thousands of dollars, were once ambulatory or mobile with the use of braces, crutches or wheelchairs. All of them with proper treatment, management and equipment could be out of bed, on wheels, out in the ward participating in programs in this institution or out in the community. With the skills and technology we now have, there is no longer any excuse for bedfast care for the cerebral palsied.
>
> It is particularly distressing for us to visit the adult wards of institutions for the retarded and recognize an individual whom we have known as a happy, bright, promising child in one United Cerebral Palsy center—severely handicapped but responsive to therapy and with potential for some measure of independent living and work under sheltered conditions. There he lies—his contractures have been allowed to take over and his body is pulled into a wierd non-functional position. His muscles have atrophied through disuse, his decubiti are ulcerating; his sad eyes stare at the ceiling with nothing to look forward to but an endless succession of purposeless tomorrows! What a waste of human potential, of time, of money! What an indictment of a society that would allow this to happen to a fellow human being!

Equally graphic—as a case illustration—of the continued neglect of the needs of retarded children is the statement before this Committee of Geraldo Rivera:

> The purpose of my testimony, I think, is just to talk about some of the conditions that exist. I can only describe them in layman's terms. I don't know about developmental disabilities and I don't know about the differences in the distinction between the moderately and mildly and profoundly retarded, but I do know when you walk into a room that is about half the size of this one that has 200 children in it and those children are smeared with their own faces and they are naked and dressed in rags and knocking their heads against the wall and there are only three or four attendants to take care of these kids, I don't have to be a specialist to know there is something wrong there.

The author of the original Bill of Rights for the Mentally Retarded (from which title II originated), Senator Jacob K. Javits, the ranking minority member of the Labor and Public Welfare Committee, personally toured Willowbrook. At his request, a special Federal team from the Department of Health, Education, and Welfare also visited Willowbrook. Its report concluded:

> Furthermore, on many of the wards that the teams visited, the care was substandard and inadequate to take care of the basic health and hygiene needs of the residents. Eye examinations seem to be particularly nonexistent. Dental care was primitive and medical services available only when crises occurred.
>
> Perhaps most disheartening of all was that there were no individualized treatment plans for most of the residents. Residents who had rehabilitation potential were left in wards without sufficient or well-trained staff to care for them.
>
> Furtheremore, since there were so few social workers on staff, there could be no real effort to work with families or residents to plan foster care and other possible alternatives to institutionalization.

The Federal team recommended that there was an urgent need to develop more community-based facilities as opposed to institutions. It also stated that immediate action is required to screen residents of all institutions and to develop and implement adequate standards of care for the treatment and training of retarded residents.

In 1967 an evaluation team of the American Association on Mental Deficiency conducted an inspection of the Partlow State School and Hospital. The report of this team included the following information regarding a visit to a ward for severely retarded ambulatory young males:

> Ground food was brought to the dayroom in a very large aluminum bowl along with nine metal plates and nine metal spoons. Nine working residents were sent in to feed these 54 young boys from this one bowl of food and nine plates and nine spoons. The feeding was accomplished in a total state of confusion. Since there were no accommodations to even sit down to eat, it was impossible to tell which residents had been fed and which had not been fed with this system.

Four years later the conditions at this hospital were substantially unchanged and led to the decision by Judge Frank Johnson in the case of *Wyatt* v. *Stickney* which first expressed the constitutional basis for minimum standards in institutions for the retarded and mentally ill.

Testimony before this Committee, testimony before Judge Johnson and reports from various surveys all indicate that most large institutions for the developmentally disabled in the U.S. lack individualized treatment plans and programs. That is, care is primarily custodial; and little attention is paid to the resident's potential for increased self care, ability to utilize education or training. All too often also drugs are used to control patients' behavior rather than for any particular therapeutic purposes.

In *Wyatt* v. *Stickney* the court initially found that the "inmates" of this mental institution were receiving inadequate treatment. Following this, the court gave the State six months to remedy the acknowledged deficiencies and to develop a plan for adequate treatment which would include the following: individualized treatment plans for all patients; a humane physical and psychological environment; and trained and qualified professional and paraprofessional staff in numbers adequate to provide treatment. The court indicated these were the minimum conditions for any treatment program.

The minimum constitutional standards for adequate treatment promulgated by Judge Johnson in March of 1972 included the following areas:

1. Right to privacy,
2. Right to the least restrictive condition necessary to achieve the purpose of confinement,
3. Rights to visitation and telephone communication as for other patients except as specifically formulated as part of a patient's particular treatment plan,
4. Unrestricted right to send sealed mail,
5. Right to be free from excessive medication,
6. Right to be free from physical restraint and isolation,
7. Right not to be subjected to experimental research without expressed and informed consent of the patient,
8. Right not to be subjected to treatment procedures such as lobotomy, electric convulsive treatment, etc. without expressed and informed consent,
9. Right to receive prompt and adequate medical treatment for any physical ailment,
10. Right to wear own clothes and keep own personal possessions,
11. Right to receive from the hospital clothing if patients don't have any of their own,
12. Right to regular physical exercise several times a week,
13. Right to religious worship,
14. Opportunities for interaction with members of the opposite sex,
15. Right to a humane psychological and physical environment (square footage of living space, toilets and lavatories, showers, dayroom, dining facilities, adequate heat, and adequate refuse facilities).

In addition, the Judge's standards set conditions under which patients could be required to perform labor which involves the operation and maintenance of the hospital. Finally, there were detailed requirements in relation to staff-patient ratios and the necessity for each patient to have an individualized treatment plan which shall be developed by a mental health professional. In addition, the Judge specified the appointment of a human rights committee for the two institutions involved.

While the case of *Wyatt* v. *Stickney* most clearly enunciated the constitutional rights involved and most specifically spelled out standards for the care of the mentally retarded, other significant cases include the following: *New York State Association for Retarded Children* v. *Rockefeller*, *Souder* v. *Brennan*, *Dale* v. *State of New York*, and *Donaldson* v. *O'Connor*.

It is interesting to note that the decision of Judge Johnson's court with regard to the right of the mentally retarded to rehabilitation, is supported not only by applicable legal authority, but also by a resolution adopted on December 27, 1971, by the General Assembly of the United Nations. That resolution, entitled "Declaration on the Rights of the Mentally Retarded" reads in part:

> The mentally retarded person has a right to proper medical care and physical therapy and to such education, training, rehabilitation and guidance as will enable him to develop his ability and maximum potential.

Dr. Philip Roos, Executive Director for the National Association for Retarded Children, in his testimony before Judge Johnson summarized his visit to the Partlow State School as follows:

> The conditions at Partlow today are generally dehumanizing, fostering deviancy, generating self-fulfilling prophecy of parasitism and helplessness. The conditions I would say are hazardous to psychological integrity, to health and in some cases even to life. The administration, the physical plants, the programs, and the institution's articulation with the community and with consumers reflect destructive models of mental retardation. They hark back to decades ago when the retarded were misperceived as being sick, as being threats to society, or being subhuman organisms. The new concepts in the field of mental retardation are unfortunately not reflected in Partlow as we see it today—concepts such as normalization, developmental model and orientation toward mental retardation, thrust of consumer involvement, the trend toward community orientation, decentralization of services: none of these are clearly in evidence in the facilities today.

New concepts, new methods, new treatment and educational approaches have been developed. They are being implemented in a number of communities and a small number of institutions for the developmentally disabled throughout the U.S. Unfortunately, however, the vast majority of institutional programs are still far from ideal, and vary greatly in quality and availability.

The inhumane and nonhabilitation aspects of these large institutions have unfortunately been graphically demonstrated over and over again. In a number of the crucial court cases, for example, the defendants were only too willing to stipulate that the conditions described by the plaintiffs were accurate. New and imaginative ways of funding are required; more stress must be place on community programs and community supervision; but at the same time the thousands of developmentally disabled residents of large institutions immediately need to have their care upgraded and improved. This is the clear thrust of all the expert testimony heard by the Committee.

The Committee is firmly convinced that Congress must take action to ensure the humane care, treatment, habilitation, and protection of mentally retarded and other persons with developmental disabilities. The Federal Government has the responsibility to provide equal protection under the law to all citizens.

It must be recognized that the vast majority of developmentally disabled persons and the vast majority of persons now institutionalized should not be in these institutions at all. Efforts to assure proper treatment, education, and habilitation services in large institutions should not deflect attention from the fact that most of these institutions themselves are anacronisms, and that rapid steps should be taken to phase them out. Many of these institutions by their very nature, their size, their isolation, their impersonality, are unsuitable for treatment, education, and habilitation programs.

The emphasis on improving care in these institutions must be paralleled by other efforts to move toward "deinstitutionalization"—towards "normalization."

Experts in the field of developmental disabilities as well as in civil rights law now agree that every effort should be made to insure that our developmentally disabled citizens are provided every opportunity of being cared for in the least restrictive setting that is consistent with the person's ability for self-care. Clearly many, if not a majority, of current residents of institutions for the mentally retarded and other developmentally disabled persons could be cared for in less restrictive institutions or facilities than are presently being employed.

Therefore, the intent of this legislation is not only to improve care in residential facilities, but also to minimize inappropriate admissions and to stimulate the States to develop alternative programs of care for mentally retarded and other developmentally disabled persons. It is clear that the provision of adequate and humane care in large State institutions, alone, is not an adequate answer to the problem. Other initiatives must include cutting off the flow of residents into such institutions by development of community alternatives.

Finally, the role of the institutions themselves should change. They should become part of total habilitative-rehabilitative systems. Institutions for the developmentally disabled should be only one alternative type of residential service which can function as a treatment-educational facility. Above all, institutions for the retarded must cease to be repositories for persons for whom nobody cares.

The Committee feels that the standards set forth in title II are minimum standards to insure basic human dignity where institutional care for developmentally disabled persons is found. It is not, however, the Committee's intent that enactment of this title should be construed in any way to constitute support of institutionalization of the mentally retarded.

It is to this end that Part B of title II provides alternative procedures and criteria and that Part D of title II provides standards for community facilities and agencies serving persons with developmental disabilities.

This title provides full flexibility to the Secretary and the National Advisory Council to review and determine the criteria by which compliance with standards shall be measured. The Committee notes that the same groups and associations that developed the minimum standards of Parts C and D are permitted and encouraged to be represented by the National Advisory Council. The flexibility of the alternative standards of Part B insure that compliance within 5 years with the standards will not be an undue hardship administratively.

Failure of Congress to respond to the needs of persons with developmental disabilities would make a mockery of our Nation's progress in such areas as equal protection and individual liberty. Therefore, the Committee is convinced that the standards provided in this legislation constitute a valid and realistic framework for improving the overall situation of this country's developmentally disabled citizens. It is the responsibility and duty of the Congress to enact this title so that this Nation can have a realistic, attainable goal towards which to strive in the field of mental retardation and developmental disabilities.

VII. TITLE II: BILL OF RIGHTS FOR THE MENTALLY RETARDED AND OTHER INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

Title II is designed to assist in the protection of the human rights guaranteed under the Constitution of those mentally retarded and other developmentally disabled individuals who require institutional care or need community facilities and programs. It also establishes alternative procedures for compliance with standards for residential and community facilities.

The goal which the standards in Parts C and D of the title seek to achieve is one of habilitation of the developmentally disabled individual who is in need of services. The alternative standards seek to measure a residential or community program's performance against the progress made by the developmentally disabled persons served.

The alternative procedures set forth in Part B do not attempt to set the criteria by which to evaluate progress or development, but only to establish minimum procedural criteria for the protection of the developmentally disabled individual who is receiving the services.

A. National Advisory Council

The National Advisory Council on Standards for Residential and Community Facilities for the Mentally Retarded and Other Individuals With Developmental Disabilities has been established to advise the Secretary on the standards, procedural and performance criteria set forth in title II. Because of the technical nature of title II, the Committee felt it necessary to have a council which consists of experts in the field of institutional and community care, as well as consumers. Technical expertise should include architects and engineers; other advisors should include psychiatrists, psychologists, and educators.

The Council is meant to play an active role in any revision of standards that might strengthen or upgrade such standards and act as an advisor for the Secretary and his staff with regard to the Administration's evaluation and enforcement of the standards and procedures set forth in this title.

B. State Plan

Title II provides two alternatives to the States: (1) the adoption of minimum standards, i.e. Parts C and D, or (2) compliance with the alternative standards contained in Part B. If neither alternative is met, all Federal funding will be lost within 5 years.

Under the State plan:

(1) A State must provide assurances to the Secretary within one year from enactment that each facility and agency within that State has adopted a plan for compliance with the requirements (i.e., meet the requirements of the minimum standards of Parts C and D, or the requirements of Part B), and the State must submit to the Secretary a plan which demonstrates how compliance will be implemented.

(2) The State must agree to do compliance reviews, and the Secretary is required to conduct validation surveys. The State plan for compliance must address the need for deinstitutionalization and for pro-

viding the adequate community services in this thrust toward deinstitutionalization. The State plan also must be found in conformance with the regular State development disabilities plan submitted by the State Planning Council to the Secretary under title I.

(3) Those facilities which opt to meet the minimum standards under Parts C and D must meet these standards within a 5-year time period.

(4) Facilities which opt to meet the alternative standards under Part B must:

> Meet such performance criteria as developed by the Secretary;
>
> Provide individualized written plans for each developmentally disabled person served by a facility or community-based agency;
>
> Assign a program coordinator who is responsible for seeing that the services ordered in the individualized written plan are provided for each individual;
>
> Ensure that a system of protective and personal advocacy is established within the State to monitor programs and protect the rights of each individual; and
>
> Meet certain minimum standards relating to family visitation, admission requirements to facilities, provision of adequate services for habilitation, and educational services.

C. Noncompliance

Section 206 provides that five years after the date of enactment of this title, no residential or community facility or agency for individuals with developmental disabilities shall be eligible to receive payments either directly or indirectly under any Federal law unless the facility meets the standards presented in Parts C and D of this title or has demonstrated to the Secretary for a reasonable period of time that it has implemented requirements of Part B of this title.

D. Alternative Criteria for Compliance

Part B establishes the procedural criteria for compliance with the intent of title II in lieu of actual compliance with standards set forth in Parts C and D.

The rationale for Part B exists in the desire of the Congress to insure that a handicapped indivudial placed in an institution or community program will receive necessary services so that such placement is beneficial to that individual.

The procedural protections and provisions of Part B place emphasis on the goal of assuring that a developmentally disabled individual benefits from the services offered by that system so that he or she may participate within normal society and be able to live with human dignity in an institution.

E. Performance Criteria

In developing the alternative procedural protections and provisions in Part B, the Committee recognizes that any standards promulgated to protect the rights and assure quality services to individuals with developmental disabilities are only as good as the results they produce and the beneficial impact they have on the lives of individuals with developmental disabilities. The Committee has therefore chosen to require certain procedural protections which will ensure that the methods by which individual services or treatment plans are provided to such individuals protect that person's rights and provide him with due process. Title II also requires adherence to certain minimal standards protecting the lives and the well-being of such individuals. The Committee reiterates the fact that all persons with developmental disabilities have the right to services and treatment which will promote their development and enable them to live normally in the community, whether or not that entails a protected environment.

In reemphasizing this right, the Committee is aware of the tragic lack of developmental services which enable most individuals with developmental disabilities to, in fact, live more normal lives. It is for this reason that the Committee has also included, as part of the requirements of Part B, compliance with certain performance criteria to be developed by the Secretary which will provide a way of measuring the impact of any services provided to a person with developmental disabilities, and of evaluating the effectiveness of such services to assist these individuals in developing their fullest potential. As part of this requirement, the Committee has directed the Secretary, under both Title I (section 121) and Title II, to develop within 18 months from the date of enactment an evaluation system which shall provide a model or models to States by which they may evaluate all services developed for and delivered to developmentally disabled individuals.

In providing this system, the Congress has mandated the development of specific criteria by which the developmental progress of a person with developmental disabilities may be measured. These criteria shall provide the basis for evaluation of the performance of an agency in delivering services to an individual. Such criteria shall measure the performance on the basis of the progress made by an individual in mastering ever more complicated tasks and developing the ability to live more normally in society. For use under title II, the Secretary shall develop detailed performance criteria and minimum compliance levels which shall be applicable to residential and community facilities and agencies, and shall be considered required standards under Part B.

F. Individual Written Habilitation Plan

As part of these provisions, Part B requires that an individualized written habilitation plan be developed for each individual who is in a residential facility or community facility or agency. This plan is similar to provisions also contained in the Rehabilitation Act of 1973 (Public Law 93–112) and assures the individual attention needed by developmentally disabled persons. Under this requirement, the Secretary shall insure that an individualized written habilitation program is developed for every individual who is in or served by a residential facility, community facility, or agency for which standards have been established under this Act.

Every plan shall be developed jointly by representatives of the facility or agency responsible for the developmentally disabled individual or his representative. Such plans shall be reviewed periodically but at least annually.

Such plans shall include the statement of long-term habilitation goals for the individual, intermediate habilitation objectives, statement of specific services to be provided, dates for initiation and anticipated duration, objective criteria and evaluation procedures. The plan is intended to provide the greatest latitude of choice for the individual and shall be written in language that is as understandable to all concerned as possible.

The individualized plan is a document by which the agency and the individual set goals for the future of that individual. The plan set forth in Section 221 is a much more detailed plan than provided in the Rehabilitation Act of 1973 because time has allowed more study of the uses of such a plan, and more information to be gathered on relevant criteria for such a plan. The plan serves as a tool not only for the development of the individual, but also as a means of evaluating the quality and performance of the program and is a necessary component if appropriate agencies are going to evaluate the system to see if it is providing a desirable outcome for the individual within that system.

G. Program Coordination

Program coordination is required by Part B in order to assure a focal point for responsibility for the implementation of the handicapped individual's written habilitation plan and to provide direction of the rehabilitation of the developmentally disabled individual. The coordinator is the person who is responsible for the implementation of the individual written program and for procuring necessary services from other agencies that are needed in this rehabilitation. It shall be the function of the coordinator to attend to the total spectrum of the person's needs and be the focal point of responsibility for the provision of services to that person.

One of the main criticisms of the delivery system for handicapped individuals pointed out in the study released by the Rand Corporation in May of 1973 was that there is a complete lack of coordination in the delivery of services to handicapped individuals. There are a myriad of government services available to most handicapped persons from income maintenance to the procuring of devices to ameliorate the disability. However, unless these services are known to the handicapped individual, they cannot be utilized.

The program coordinator is an integral part of any service delivery system that is designed to help the handicapped individual progress. The focal point of responsibility for the individual has to be pinpointed for the delivery system to be responsible.

H. Protection and Personal Advocacy

The Committee further recognizes that there is an inherent conflict in the role a State must play in delivering services and administering programs for persons with developmental disabilities and in protecting the human and legal rights of such persons. The Committee also believes that it is most important to distinguish between these two roles in light of the nature and the problems confronting such persons who are not able to adequately protect their own rights. It is for this reason that the Committee requires the establishment of a protective and personal advocacy function by the State. The protective and personal advocacy agency or agencies required by this provision shall be independent of any State agency administering or delivering services to developmentally disabled persons.

This newly established agency shall have the authority to review all complaints regarding infringement of human rights, denial of benefits, and any other complaint on the part of an individual. Decisions of this independent agency shall be subject to appropriate judicial review. Such a protective and personal advocacy is needed to provide a mechanism by which a developmentally disabled individual within the delivery system has the means to reach outside of the established delivery system for examination of situations in which his rights as an individual citizen may be being violated.

I. Minimum Standards

The Committee feels that in order to protect the individual's health, safety and human dignity and the civil or human rights of the person, certain minimum standards have been established for the use of the alternative procedures. These minimum standards set forth certain physical requirements for the facilities opting to use Part B procedures and provides certain minimum protections of the human rights of the individual. The Committee feels that these are the absolute minimum standards under which the Federal Government can provide funding and not violate the Constitutional rights of the individuals in those programs.

J. Standards for Residential Facilities, and Community Facilities and Agencies Serving the Mentally Retarded

The Committee is aware that the present institutional system in this nation is woefully inadequate to meet the needs of the mentally retarded and developmentally disabled population. In response to the situations which exist in Willowbrook, Partlow, and Rosewood and many other facilities in this country, which when examined closely provide shocking headlines, the Committee is adopting minimum standards for such institutions.

These minimum standards for residential facilities and community facilities and agencies have been developed by the major accrediting councils and associations in the field of care for developmentally disabled individuals. These are *minimum* standards guided by the principal of normalization of persons with developmental disabilities, which insure that persons receiving services from residential facilities are protected from violation of their human and civil rights. They are the fruition of a partnership of governmental agencies, of professional organizations of practitioners in the field, and of consumer representatives, working together in the interest of improving service to mentally retarded and other developmentally disabled persons. At the same time, they stimulate States to establish plans for community and regional programs for this population and minimize admissions to the institutional residential facilities while providing funds for alternative programs of community care.

There have been many recent advances in the field of residential services to developmentally disabled persons, including the establishment of new modes of care such as the group home and the halfway house. The committee anticipates that progress in this area will continue to occur, and that these standards are the beginning of a goal we all seek—treatment and care of developmentally disabled individuals which is humane, healthful, and appropriate.

Finally, the Committee believes that the Federal Government has an obligation to implement and honor the commitment to provide humane care and treatment to the institutionalized mentally retarded and other individuals with developmental disabilities, and to deemphasize long-term institutionalization.

SECTION-BY-SECTION ANALYSIS

Section 1.—Provides that the short title of this legislation is the "Developmentally Disabled Assistance and Bill of Rights Act."

Section 2.—Contains definitions taken from section 401 of Public Law 91–517, changes some definitions, and adds new ones. It adds as new definitions: "State Planning Council", "Specific learning disability," "Institution of higher education," "Satellite centers" and "Design for implementation"; it rewrites the definitions on "developmental disability" and "poverty areas."

Section 3 (Audit).—Requires each recipient of a grant or contract to keep appropriate records. It is similar to section 408 (a) and (b) in existing law.

Section 4 (Advance Funding).—Provides authority for funds to be appropriated one year prior to the fiscal year to which they apply and for which they are obligated. For the purpose of transition to the forward funding concept, the appropriations act for the first year may contain funding for both that year and the next succeeding fiscal year.

Section 5 (Employment of Handicapped Individuals).—This section requires the Secretary to insure that recipients of assistance under this Act shall have affirmative action for the employment and advancement of handicapped individuals on the same basis as is required under the Rehabilitation Act of 1973 for State agencies, rehabilitation facilities, and Federal contractors.

Section 6 (Recovery).—Is the same as in existing law. The United States shall be entitled to recover an amount determined by a formula if the facility is sold, transferred, or ceases to be a UAF or satellite center.

Section 7 (Maintenance of Effort).—States that an application must contain reasonable assurances that a grant will not result in any decrease in the level of State, local, and other non-Federal funds for services to persons with developmental disabilities and training of professional personnel.

TITLE I—ASSISTANCE FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

Section 100 (Declaration of Purpose and Federal Share).—Describes in general terms the goals of most of its provisions, including developing and implementing a comprehensive and continuing State plan; renovation and modernization of university-affiliated facilities and support of demonstration and training programs; development of regional community programs; support of activities demonstrating exemplary services to persons with developmental disabilities who are especially disadvantaged; technical assistance; training of specialized personnel; and developing or demonstrating new or improved techniques for delivery of services to developmentally disabled persons. Subsections (b), (c), and (d) concern Federal share. The Federal share under Parts A and B may not exceed 70%, with the exceptions that projects of national significance and services to a poverty area under Part B may not exceed 90%. (Section 119(b) states that the Secretary may pay "part or all of the cost of special projects".) The non-Federal share may be in cash or in kind. Expenditures by political subdivisions of a State or by nonprofit private agencies, organizations and groups shall be considered expenditures by a State or university-affiliated facility for the purpose of determining Federal share.

In determining the amount of payment under Part A, there shall be disregarded: (a) any portion of the costs of such renovation or modernization financed by other Federal funds; (b) the amount of any non-Federal funds provided under any other provision of law; and (c) the amount of any non-Federal funds required to be expended as a condition of receipt of such Federal funds. In determining the amount of any State's Federal share of expenditures under Part B, there shall be disregarded: (a) any portion of such expenditures financed by other Federal funds, and (b) the amount of any non-Federal funds required to be expended as a condition of receipt of such Federal funds.

Finally, payments may be made in advance, except that such adjustments as may be necessary shall be made on account of previously made underpayments or overpayments.

PART A

Section 101 (*Renovation and Modernization*).—Authorizes $6,500,000 for FY 1975 and a like amount for the next four succeeding fiscal years for modernization and renovation of UAF's and satellite centers, and for utilization of existing buildings for satellite centers. Such modernization and renovation must comply with Public Law 90–480, relating to architectural barriers.

Section 102 (*Demonstration, Training, and Operational Grants*).—Authorizes grants to University Affiliated Facilities to cover part of the cost of administering and operating demonstration facilities and interdisciplinary training programs with emphasis upon the ability and commitment of such programs to provide services not otherwise available to persons with developmental disabilities in programs of community care as alternatives to such services being provided in institutionalized settings. The grantee must submit a full report no later than six months after the date of such grant on an assessment of need for community care services for persons with developmental disabilities in each State not now served by the grantee in the general geographical area in which the institution is located, and a feasibility study of ways in which grantees, singly or together, can establish and operate satellite centers in the area. Grants may also be made to UAF's to cover part of the costs of administering and operating satellite centers meeting the specifications developed in the needs assessment and feasibility studies. The authorization level for FY 1975 and each of the four succeeding fiscal years is $25,000,000, of which for FY 1975 an amount in excess of $4,250,000 and less than $4,975,000 is to be used to carry out the assessment and feasibility studies. (Subject to the availability of funds, the Secretary shall include in each grant an additional amount—not in excess of $25,000—necessary to pay all of the cost of such assessment and study.) After

FY 1975, $4,250,000 shall be available for the administration and operation of demonstration facilities and interdisciplinary training programs; of any amount in excess of this amount, 50% is to be used for satellite centers.

Section 103 (Applications).—Delineates the assurances which each application for a grant under Part A must contain, the provision for review and comment by the State Planning Council and the priority goals which applications must establish. An application must be supported by reasonable assurances that (1) it is consistent with the appropriate State plan; (2) the facility will be associated with a medical center or institution of higher education; (3) the plans and specifications are in accord with regulations promulgated pursuant to this Act; (4) title to the site for the project is or will be vested in the State, or the agency or institution making the application or operating the facility; (5) the non-Federal share of renovation or modernization will be available upon completion of the project; (6) the facility will comply with standards pursuant to the Architectural Barriers Act of 1968 and with regulations of the Secretary of Labor relating to occupational health and safety standards; and (7) any laborer or mechanic employed by a contractor or subcontractor must be paid wages in conformance with the Davis-Bacon Act, as amended. The State Planning Council must review and comment on the application before the Secretary can approve it. If the Council fails to complete its review and comment within 30 days after submission, the applicant may request the Secretary to approve the application; and if the Secretary finds that the Council's failure is "arbitrary, capricious, or unwarranted," he may approve the application himself. If the Secretary finds otherwise, he shall return the application to the Council for action. The priority goals which the applicant must meet are: (1) deinstitutionalization and development of community-based programs; (2) early screening, diagnosis and evaluation of infants and preschool children; (3) counseling, client program coordination, follow-along services, protective services, and personal advocacy for adults; and (4) normalization of institutional life.

PART B

Section 111: (Authorization of Appropriations).—Authorizes $50,000,000 for FY 1975; $85,000,000 for FY 1976; $95,000,000 for FY 1977; $100,000,000 for FY 1978; and $110,000,000 for FY 1979, plus such additional sums as Congress deems necessary, for grants for planning, provision of services, and construction and operation of facilities for persons with developmental disabilities.

Section 112 (State Allotments).—Entitles the States to allotments based on (a) the population, (b) the extent of need for services and facilities for persons with developmental disabilities, and (c) the financial need. The minimum allotment for the States is $200,000; the minimum allotment for the territories is $50,000. No State shall receive less than it received in FY 1974. The minimum is to be increased if appropriations after FY 1975 exceed $50,000,000; the percentage increase is the same as the percent by which the appropriations of that particular year exceeds the FY 1975 authorization of $50,000,000. In determining the need for services and facilities, the Secretary shall take into account the scope and extent of services specified in the State plan.

In addition, funds designated by a State as construction funds during a fiscal year are to remain available to the State in the following fiscal year. A State may apportion its allotments for services (but not for construction) among more than one State agency in carrying out the State plan. Also, States may pool their allotments to carry out cooperative interstate efforts. Subsection (d) permits the Secretary to transfer funds not used by one State to one or more other States after a 30-day notice given in the Federal Register.

Subsection (e) continues the existing authority for projects of national significance, reserving up to 10% of the total appropriation for Part B. These grants shall be made after consultation with the National Advisory Council. The Federal share of such projects is retained at 90%. Such projects shall include integrated service model projects; and demonstration projects to coordinate and utilize all available community resources. All grants are to be made by the Secretary in accordance with policies used generally to administer grants throughout the Department of Health, Education, and Welfare.

Section 113 (The National Council on Service and Facilities for the Developmentally Disabled).—Establishes a 25-member National Council, consisting of 9 designated members (Deputy Commissioner of the Bureau on Education for the Handicapped, the Commissioner of the Rehabilitation Services Administration, the Administrator of the Social and Rehabilitation Service, the Director of the National Institute of Child Health and Human Development, the Director of the National Institute of Neurological Disease and Stroke, the Director of the National Institute of Mental Health, and three other representatives of the Department of Health, Education, and Welfare) and 16 citizen members. Each member is appointed for a term of four years unless he is appointed to fill a vacancy in which case he shall serve the remainder of the term. All vacancies must be filled within 10 calendar days of the occurrence of such vacancies.

The National Council shall meet at least twice a year, shall engage such technical, secretarial, clerical and other assistance as needed, and shall: (1) advise the Secretary with respect to regulations developed pursuant to this Act; (2) study and evaluate programs; (3) monitor the development and execution of title I; (4) review and advise the Secretary regarding grants of national significance and the model evaluation system; and (5) report annually directly to the Congress on the efficiency of the administration of title I. There is an authorization of $100,000 for each fiscal year of the bill for the Council.

Section 114 (State Plans).—Mandates that the State plans must include provisions to: (1) reduce and eventually eliminate inappropriate institutional placement; (2) improve the quality of care and rehabilitation for those who must remain institutionalized; (3) provide early screening, diagnosis and evaluation; (4) provide counseling, client program coordination, follow-along services, protective services, and personal advocacy services for adults; (5) support community programs as alternatives to institutionalization; (6) protect the human rights of persons with developmental disabilities; and (7) provide for interdisciplinary intervention and training programs.

A State plan shall: (1) designate the State agency or agencies which shall administer and supervise the administration of the State plan; and designate the single State agency responsible for the administration of construction, renovation or modernization grants; (2) describe the quality, extent and scope of services being provided; (3) describe the quality, extent and scope of services being provided under other Federal laws to developmentally disabled individuals and show how funds under this Part will be used to complement and augment such services; (4) provide for the maximum utilization of all available community services (including volunteers) with the proviso that volunteer services shall supplement the services of paid employees; (5) set forth policies and procedures for the expenditure of funds; (6) contain assurances that the funds will be used to make a significant contribution toward strengthening services for persons with developmental disabilities, that the funds may be made available to other public or nonprofit private agencies, institutions and organizations, that the funds will be used to supplement and increase the level of funds otherwise available, and that there will be reasonable State financial participation; (7) provide that services and facilities furnished under the plan will be in adherence with standards prescribed by the Secretary under title II of this Act; (8) provide such methods of administration as are found to be necessary for the proper and efficient operation of the plan; (9) provide assurances that the State Planning Council is assigned adequate personnel to carry out its duties; (10) provide assurance that the State Planning Council shall at least annually review and evaluate the State plan; (11) provide that the administering State agencies will keep such records as are necessary; (12) provide that special financial and technical assistance shall be given to urban or rural poverty areas; (13) describe the methods to be used to assess the effectiveness and accomplishments of the State in meeting the needs of the developmentally disabled community; (14) specify the maximum amount of and percentage of a State's allotment which is to go to construction, modernization or renovation (not more than 10% of the State's allotment); (15) provide reasonable assurance that adequate financial support will be available to complete the construction of, and to maintain and operate, any facility assisted by funds under this part; (16) outline (if funds are to be used for construction, renovation or modernization) a program which is (a) based on a State-wide inventory of existing facilities and survey of need; (b) sets forth the relative need for several projects; (c) assigns priorities in the order of relative need, taking into account the requirement that such construction, renovation or modernization complies with standards prescribed pursuant to the Architectural Barriers Act of 1968; (17) provides an opportunity for a hearing to every applicant for a construction, renovation or modernization project; (18) provides for such accounting procedures as may be necessary; (19) provides for the implementation of an evaluation system similar to that developed at the national level within 30 months after the date of enactment of this Act; (20) provides, to the maximum extent feasible, an opportunity for prior review and comment by the State Planning Council of all State plans concerning persons with developmental disabilities; (21) provides that personnel assigned to the State Planning Council shall be responsible solely to the Council; (22) provides that all relevant information concerning other programs relating to persons with developmental disabilities is available to the State Planning Council; (23) provides fair and equitable arrangements to protect the interests of employees affected by the State plan; and (24) contains such additional information as is necessary.

The Secretary may not disapprove a State plan unless he has provided reasonable notice and opportunity for a hearing to the State.

Section 115 (State Planning Council).—Establishes State Planning Council which is to serve as an advocate for persons with developmental disabilities. The Council is to be appointed by the Governor of each State.

The State Planning Council shall (1) develop and prepare the State plan; (2) approve, monitor, and evaluate the implementation of the State plan; (3) establish priorities for the distribution of funds; (4) review and comment on all State plans in the State which concern persons with developmental disabilities; and (5) submit to the Secretary, through the Governor, any periodic reports the Secretary may reasonably request.

At least 20% but no more than 30% of the amount of the State's allotment shall be used for personnel assigned to the Council. The membership shall include representatives of the principal State agencies, local agencies, and nongovernmental agencies and groups concerned with services to persons with developmental disabilities, including a representative of an institution of higher education receiving a grant. At least one-third of the membership must consist of consumers of services, or their parents or guardians if they are not officers of an organization or employees of an agency which receives funds under this Act.

The administering State agency or agencies must submit to the State Planning Council for approval the design for implementation, including a detailed plan for the disbursement of funds. Finally, the Secretary shall insure that each State Planning Council has access to all other State plans relevant to the developmental disabilities program.

Section 116 (Withholding of Payments).—States that if the Secretary finds after reasonable notice and opportunity for a hearing: (1) that any State agency or agencies are not complying with the provisions of the State plan or the regulations of the Secretary; (2) that any requirement set forth in an application under section 114 is not being or cannot be carried out; or (3) that adequate funds are not being provided annually for the direct administration of the State plan, he may notify the State council and State agency or agencies that payments are being withheld for any project affected by the action or inaction. Whenever the State planning and advisory council finds that a State agency administering funds is failing to comply with the design for implementation, the council shall notify the Governor and the Secretary, who in turn may provide notice, conduct a hearing, and withhold payments.

Section 117 (Regulations).—Directs the Secretary to promulgate regulations pursuant to this Act no later than 90 days following enactment. The regulations may be waived if the Secretary finds that they would impede the implementation of a project which is consistent with the goals of this legislation. The waivers are to be reviewed annually by the Secretary and issued on a case-by-case basis and for a specified period of time, but in no case longer than 36 months. Renewal of such waivers may be granted only after a full evaluation of the full impact of the waivers. The Secretary shall submit his justification for a renewal of waivers to the appropriate committees of Congress. In addition, the Secretary shall publish in the Federal Register the fact that a waiver application has been submitted by a State, and he shall not approve or disapprove this application in less than 60 nor more than 90 days after the publication date.

Section 118 (Evaluation of Developmental Disabilities Services).—Mandates the development by the Secretary, in consultation with the National Council, of (a) a design for a comprehensive system for the evaluation of services for persons with developmental disabilities, and (b) a time-phased plan for each State's implementation of a minimal evaluation system by October 1, 1977. This plan will further specify the phases leading to the establishment (36 months after the date of enactment of this Act) of a comprehensive evaluation system in each State.

The evaluation system shall be designed to (1) provide objective measures of the progress of persons with developmental disabilities; (2) provide objective evaluation of living environments and associated services of persons with developmental disabilities; and (3) provide specific criteria to use as compliance levels for operating residential and community facilities and agencies.

Not later than February 1, 1977, the Secretary shall submit to the Congress a report on the evaluation system design, including an estimate of the costs of developing and implementing the system. The Secretary may make grants to and enter into contracts with public and private nonprofit organizations and individuals to conduct feasibility studies to assist in developing the system; and $1,000,000 for each of the fiscal years 1976 and 1977 are available for the purposes of section 118.

Section 119 (Grants for Special Projects for Services to Persons with Developmental Disabilities).—Authorizes $17,500,000 for FY 1975; $20,000,000 for FY 1976; $22,500,000 for FY 1977; $25,000,000 for FY 1978; and $27,500,000 for FY 1979 to pay part or all of the cost of special projects and demonstrations. Such projects and demonstrations shall include, but not be limited to, parent counseling and training, early screening and intervention, infant and pre-school programs, seizure control system, legal advocacy, community-based counseling, care, housing, and other services and systems necessary to maintain a person with developmental disabilities in the community. The Secretary must insure that any special projects are reviewed and commented on by the appropriate State Planning Council. Finally, any project or part thereof funded under this section shall not be eligible for funding under section 304 of the Rehabilitation Act of 1973.

Section 120 (Repeal).—Parts B and C of the Developmental Disabilities Services and Facilities Construction Act are repealed 90 days after enactment of this Act.

TITLE II—BILL OF RIGHTS FOR MENTALLY RETARDED AND OTHER PERSONS WITH DEVELOPMENTAL DISABILITIES

Section 200 (Statement of Purpose).—States the purpose of title II—to establish standards to assure the humane care, treatment, habilitation, and protection of mentally retarded and other persons with developmental disabilities who are served by residential and community facilities and agencies; to establish a method to assess compliance with such standards; and to minimize inappropriate admissions to such facilities and agencies, through establishment of assurances that standards affecting health, safety, personal dignity, and human and civil rights of persons with developmental disabilities are being complied with by such facilities and agencies. This will be done through the use of procedural criteria set forth in part B and performance criteria developed by the Secretary pursuant to section 210; through compliance with minimum standards set forth in section 215; and through such additional criteria that the Council and the Secretary may deem necessary; or through compliance with standards set forth with parts C and D.

Part A—General Provisions for Residential and Community Facilities and Agencies Serving Mentally Retarded and Other Persons with Developmental Disabilities

Section 201 (Definitions).—Describes the meanings of the following terms for the purposes of the title:

(1) Adaptive behavior;
(2) Agency;
(3) Body image;
(4) Person, disabled person, or disabled;
(5) Program coordinator;
(6) Community;
(7) Cross-disciplinary approach;
(8) Culturally normative;
(9) Family;
(10) Generic services;
(11) Governing board, board of trustees, board of directors, or board of governors;
(12) Governing body;
(13) Guardian;
(14) Guardian of the person;
(15) Guardian of the property;
(16) Legal guardian;
(17) Natural guardian;
(18) Plenary guardian;
(19) Public guardian;
(20) Testimentary guardian;
(21) Guardian ad litem;
(22) Indigenous leadership;
(23) (A) Informed consent;
    (B) Exceptional cases;
(24) Interdisciplinary approach;
(25) Multidisciplinary approach;
(26) Mapping;
(27) Mental retardation;
(28) Mobile nonambulatory;
(29) Nonambulatory;
(30) Normalization principle;
(31) Orientation;
(32) Program;
(33) Residential facility;
(34) Service delivery system;
(35) Advocate;
(36) Ambulatory;

(37) Chief executive officer;
(38) Developmental disability;
(39) Direct-care staff;
(40) Legal incompetence;
(41) Living unit;
(42) Nonmobile;
(43) Public financial support programs;
(44) Resident;
(45) Resident-living;
(46) Rhythm of life;
(47) Surrogate; and
(48) Time out.

Section 202 (National Advisory Council on Standards for Residential and Community Facilities for Mentally Retarded and Other Persons with Developmental Disabilities).—Provides for the establishment of a 15-member National Advisory Council on Standards for Residential and Community Facilities for Mentally Retarded and Other Persons with Developmental Disabilities. Members will be selected from public agencies providing services to developmentally disabled persons and from professional and voluntary associations representing such persons. At least one-third of the membership will be consumers of services.

The Council will advise the Secretary on regulations implementing standards, will study and evaluate such standards through site visits and other methods to determine their effectiveness, and will assist the Secretary in developing performance criteria to evaluate alternate standards under Part B and section 121.

Based upon its studies, evaluations, and other review mechanisms, the Council will submit recommendations for changes or improvements in standards under parts C and D of the title to strengthen or upgrade them.

Members of the Council will be compensated, and the section authorizes appropriation of such sums as may be necessary to carry out the purposes of the section.

Section 203 (Assessing Compliance with Standards).—Subsection (a) requires that a State, in determining whether a federally-assisted facility or agency in its jurisdiction is in compliance with standards specified in this title, shall provide assurances to the Secretary within one year after the date of enactment that each such facility or agency has a plan for achieving compliance no later than 5 years after the date of enactment and is pursuing program to comply with standards in parts C and D, or meets requirements set forth in part B.

In further demonstrating compliance, each State shall submit a plan based on the combined plans of all such facilities and agencies setting forth detailed procedures for compliance and under which the State agrees to meet provisions for reviews as may be required.

Section 203(b) provides that each State plan shall—

(1) Provide a detailed analysis of steps each facility or agency will take to comply with part B, or parts C and D;

(2) Set forth a detailed schedule for compliance with such standards based on the analysis submitted pursuant to clause (1);

(3) Demonstrate the need for continuing residential services and provide detailed assurances that residential facilities for individuals

with developmental disabilities will complement and augment rather than duplicate or replace other community services and facilities for such individuals which meet the requirements of the title;

(4) Designate a single State agency to oversee compliance;

(5) Provide that such State plan has been submitted to the State planning council established under section 115 of the Act for review and comment and has been found to be in conformance with the State plan required under section 114(b);

(6) Set forth a schedule of costs to achieve compliance under part B or parts C and D;

(7) Demonstrate procedures adopted by the State to assure that primary emphasis be given to placing each individual in the least restrictive program and living environment commensurate with individual capabilities and needs, and that any assistance available under State or Federal law under which services are provided to persons with developmental disabilities will be utilized to foster carrying out such procedures;

(8) Set forth the detailed performance criteria to be used in assessing the quality of services, provided that such criteria conform to those under section 210;

(9) Provide an explanation of the system to be used for gathering, analyzing, and interpreting information and data for compliance review; and

(10) Provide assurances that all subjective judgments concerning quality of services rendered will be made by qualified individuals not employed by, or financially obligated to, the agency responsible for operating the programs.

Section 203(c) provides for approval of plans which set forth a reasonable time subject to section 206 for compliance and provides that plans will not be disapproved without reasonable notice and opportunity for a hearing.

Section 203(d) requires each State to enter an agreement with the Secretary under which the designated State agency will be utilized to determine whether a facility or agency is in compliance with standards under part B or parts C and D, such determination to be made on the basis of onsite surveys by the State agency. Any such State agency may furnish to the facilities and agencies such specialized consultation services needed to meet established standards. The Secretary will make public the findings of each survey within 90 days of completion.

In order to assure compliance with standards under part B or parts C and D and the performance criteria under section 210, the Secretary shall conduct a compliance survey of facilities and agencies within each State to determine accuracy of information and data submitted.

Each year the Secretary must submit an annual report to appropriate Congressional committees summarizing—numbers and types of facilities and agencies found in compliance and not in compliance with standards under part B or parts C and D; reasons for noncompliance and steps being taken to assure compliance; finding of validation surveys; numbers and types of facilities and agencies found to be ineligible for Federal assistance because of failure to comply with standards; and recommendations for alterations in the compliance review system and supporting evidence for such alterations or change.

Section 204 Grants To Assist Compliance.—Authorizes appropriations of such sum as may be necessary for grants to assist States in bringing publicly operated and Federally assisted residential or community facilities and agencies into compliance with standards established under the title. A State applying for such a grant must provide detailed information which shows how such grant will assist in meeting the standards. The total of the grants for any project may not exceed 75 percent of the necessary cost as determined by the Secretary. Payments of grants shall be made in advance or by way of reimbursement, and on such conditions as the Secretary may determine.

Section 205 (*Maintenance of Effort*).—Provides for maintenance of effort by the States, that payments to any facility under the grants will not result in any decrease in per capita State and local expenditures for services for developmentally disabled individuals which would otherwise be available to such facility. The Section provides for an annual report to Congressional committees summarizing maintenance of effort by States and facilities.

Section 206 Withholding of Grants.—Provides that after December 31, 1979, no residential facility or program of community care for developmentally disabled individuals shall be eligible for payments directly or indirectly under any Federal law unless such facility meets standards under part C or D or has demonstrated for a reasonable period that it has actively implemented requirements of part B.

The section provides that any funds to which a person would otherwise be entitled to have paid on his behalf to a residential facility or program of community care will be reserved for him and administered by the Social Security Administration in the same manner as benefits under title II of the Social Security Act would be administered on his behalf if he were entitled to them.

Section 207 Evaluation and Performance Criteria.—Directs the Secretary, in consultation with the National Advisory Council to develop and transmit to Congress within 18 months after enactment an evaluation system and plan for implementation designed to: assess the adequacy of all education and training, habilitation, rehabilitation, early childhood, diagnostic and evaluation services, or any other services or assistance under all laws administered by the Secretary; and develop specific criteria designed to provide objective measurement of the developmental progress of a developmentally disabled individual, to be utilized by agencies and facilities to evaluate effectiveness of services provided.

In developing this evaluation system, the Secretary must insure that it is consumer oriented and is designed to—

(1) Evaluate the effects of services on the lives of consumers, using information and data obtained from individualized written habilitation plans as required under section 211,

(2) Evaluate overall impact of State and local programs for the developmentally disabled,

(3) Provide and evaluate the cost-benefit ratios of particular service alternatives, and

(4) Provide that evaluation of program quality shall be performed by individuals not directly involved in the delivery of such services to the program being evaluated.

This section authorizes appropriations of $1 million each for fiscal year 1975 and the succeeding fiscal year for grants and contracts for feasibility studies to assist in developing the evaluation system, except that such grant or contract shall not be entered into with groups or individuals who are directly related the program being evaluated.

Part B—Alternate Criteria for Compliance in Lieu of Standards for Residential and Community Facilities and Agencies

Section 210 (Performance Criteria).—Directs the Secretary to specify detailed performance criteria for measuring and evaluating developmental progress of a developmentally disabled person who is receiving direct service in a residential or community based facility or agency and minimum compliance levels for such criteria to be applicable to such facilities and agencies. Such performance criteria shall be developed pursuant to section 203 and be considered, along with minimum compliance levels, as required standards under this part.

Prior to approving any compliance plan submitted under section 203, the Secretary shall obtain adequate assurance of compliance with the performance criteria developed under such section.

Section 211 (Individualized Written Habilitation Plan).—Subsection (a) directs the Secretary to insure that an individualized written habilitation plan is developed and modified at frequent intervals on behalf of each person who is in a facility or agency for which standards have been established under the Act or under any other federally assisted State or local program specified by the Secretary.

Subsection (b) directs that each individualized plan shall be developed jointly by the facility or agency responsible for delivery or coordination of delivery of services to the person and the developmentally disabled person (or, where appropriate, his parents or guardians). In any case in which such person is receiving services from two or more agencies, the agency primarily responsible for delivery of services will also be responsible for insuring that all services are part of the individualized plan.

Subsection (c) provides that each individualized plan shall be reviewed at least annually by the "primarily responsible" agency, at which time the person, or his parents or guardians, will have the opportunity to review it and jointly redevelop its terms. Such plan shall include but not be limited to (1) a statement of long-term goals for the person and intermediate objectives related to attainment of such goals, (2) a statement of specific services to be provided, (3) projected date for the initiation and anticipated duration of each service, and (4) objective criteria and evaluation procedure and schedule for determining whether such objectives and goals are being achieved.

Subsection (d) lists the basic criteria that each individualized plan shall conform to:

(1) The initial plan shall be developed upon a person's application for service;

(2) The plan shall reflect use of assessment data in at least the following areas of development—sensor-motor, communicative, social, affective, and cognitive;

(3) The objectives of the plan shall be developed with the participation of the person, his family or guardian, all relevant agency staff members, and staff of other involved agencies;

(4) Objectives of the plan shall be stated separately, started in sequence with specific time periods, and expressed in behavioral terms that provide measurable indices of progress;

(5) The plan shall describe conditions, activities, or barriers interfering with achievement of objectives;

(6) The plan shall specify modes of intervention for achievement of stated objectives;

(7) The plan shall identify agencies delivering services required;

(8) The plan shall identify a designated focus of responsibility for using and coordinating services provided by different practitioners or agencies;

(9) The plan shall include a specification of proposed day-to-day training activities designed to assist in attaining objectives;

(10) The plan shall be written in functional terms understandable to the person, or parents or guardians;

(11) The plan shall be reviewed at least quarterly to measure progress, modify objectives as necessary, determine needed services, and provide guidance and remediation techniques to modify barriers to growth; and

(12) The plan shall include a written agreement specifying role and objectives of each party to the implementation of the individualized written habilitation plan.

Subsection (e) directs the Secretary to insure that, in developing and carrying out each plan, primary emphasis will be given to placing the person in the least restrictive program and living environment commensurate with his capabilities and needs.

Subsection (f) directs the Secretary to specify detailed performance criteria for measuring and evaluating developmental progress of developmentally disabled persons attained through the use of such individualized plans.

Section 212 Program Coordination.—Subsection (a) provides that each person served by an agency shall be assigned a program coordinator responsible for implementing the person's individual plan. The coordinator's services shall be terminated only when responsibility for service has been assumed by another agency, at which time a new coordinator shall be assigned.

Subsection (b) directs each agency to insure that—

(1) The person or his family participate in selection of the coordinator and the coordinator shall be identified to the person, his family and appropriate staff members;

(2) The coordinator shall attend to the total spectrum of the person's needs, and shall determine whether the person's needs are being met and how;

(3) The coordinator shall provide supportive services to the person and his family;

(4) To keep the individual plan up to date, the coordinator shall secure relevant data from other agencies providing service;

(5) The coordinator shall provide documentation relevant to the review of the individual plan; and

(6) The coordinator, or another agency staff member, shall assist the person, or his family or guardian, in planning for and securing living arrangements adapted to the person's needs.

Section 213 Protective and Personal Advocacy.—Subsection (a) directs the Secretary to insure that a system of protective and personal advocacy is established in each State to monitor programs and services and protect the human and legal rights of each person served by facilities or programs within the State.

Subsection (b) directs the Secretary to insure that for each such system an agency or entity is designated which is independent of any service-providing agency, is capable of providing protective and personal advocacy services, and shall be responsible for monitoring and auditing the individualized programs of persons to insure that they receive all benefits, services, and rights that they are entitled to under any law or program.

Subsection (c) requires each such system to include an independent entity with the authority to receive all complaints regarding infringement of rights, denial of benefits, or failure to provide necessary services. Each such entity will have the power to render decisions respecting complaints, such decisions to be final and binding. Prior to issuance of any order or decision, any affected party may request a hearing, to be held within 60 days of the receipt of complaint, and such order or decision to be rendered within 60 days after the hearing is concluded. Such order or decisions is subject to appropriate judicial review.

Section 214 (Record Requirements).—Requires residential and community facilities and agencies to keep such records appropriate to evaluate the effectiveness of performance and compliance with the provisions of this part.

Each facility and agency shall identify the number of developmentally disabled persons rejected for services by the facility or agency, and the reasons for each such rejection, and report such information every 6 months to the Secretary and the State.

Section 215 (Minimum Standards for Use with the Alternate Procedure).—Provides that each residential and community facility and agency choosing to use the alternate procedures of this part in lieu of compliance with parts C and D must comply with the following minimum standards to insure—

(1) That close relatives be permitted to visit a person at any reasonable hour and without prior notice provided that privacy and rights of other residents and persons are not infringed.

(2) Implementation of advocacy for all residents and persons;

(3) That no individual whose needs cannot be met by the residential facility or agency shall be admitted to it;

(4) That the number of persons admitted as residents or persons to the facility or agency shall not exceed its rated capacity and provisions for adequate programing;

(5) That there is a regular joint review of the status of each resident or person by all relevant personnel, including those in the living unit with program recommendations for implementation, including consideration of advisability of continued residence and alternative programs, and at the time of the resident's attained majority, or if he becomes emancipated prior thereto, his need to remain in the facility, his need for guardianship, and the protection of his civil and legal rights;

(6) That mistreatment of residents and persons shall be strictly prohibited, that any such mistreatment shall be reported immediately by the facility or agency to the State, that all such incidents shall be investigated through an established procedure consistent with due process, the results to be reported to the chief executive officer within

24 hours, and appropriate sanctions when such allegations are substantiated;

(7) That living unit personnel shall train residents and persons in daily living activities and in the development of self-help and social skills;

(8) That living unit personnel shall be responsible for development and maintenance of a warm, family or home-like environment conducive to achievement of optimal development;

(9) That the rhythm of life in the living unit shall resemble the cultural norm of the resident's or person's nonretarded or nondevelopmentally disabled age peers, unless a departure is justified on the basis of maximizing human qualities;

(10) That residents and persons shall be assigned responsibilities in the living unit commensurate with interests, abilities, and developmental plans, to enhance self-respect and to develop skills of independent living, and that multiple-handicapped and nonambulatory residents shall spend a major portion of the waking day out of bed, a portion of the day out of bedroom areas, and have planned daily activity and exercise periods;

(11) That residents and persons shall be provided with systematic training to develop appropriate eating skills using adaptive equipment when appropriate;

(12) That, in accordance with the normalization principle, all professional services to mentally retarded and others with developmental disabilities shall, where feasible, be provided in the community, rather than in the residential facility, and where provided in such a facility, such services must be at least comparable to those provided in the community;

(13) That educational services shall be available to all residents and persons regardless of age, retardation, or other disabilities, and for residents or persons of legal school age, the State shall insure that the State educational agency provides educational services equivalent to those provided in the nonhandicapped population;

(14) That special attention shall be given those residents and persons who without active intervention, are at the risk of further loss of function, including—

(A) Early diagnosis of disease;
(B) Prompt treatment in early stages;
(C) Limitation of disability by arresting disease process;
(D) Prevention of complications and sequelae; and
(E) Rehabilitation services to raise the resident or person to his greatest possible level of function in spite of handicap, by maximizing the use of existing capabilities.

(15) That the civil rights of all residents be assured;

(16) That physical and mechanical restraint be employed only in accordance with written policy and never as punishment or substitute for a program;

(17) That chemical restraint not be used excessively, as punishment, or as a substitute for a program;

(18) That a nourishing, well-balanced diet shall be provided all residents;

(19) That medical and dental services shall be provided to all residents;

(20) That adequate fire and safety standards be met;

(21) That paint used in facilities be lead free; and

(22) That there shall be adequate sanitation and waste disposal.

Part C—Standards for Residential Facilities for Mentally Retarded and Other Persons With Developmental Disabilities

Chapter I—Administrative Policies and Practices

The first subchapter of Chapter I (sections 220 through 223) describes the standards for the philosophy under which a residential facility should operate, and the standards under which such a facility should be located and operated. These standards stress the fostering of humanization of mentally retarded residents and the importance of providing as normal an atmosphere as possible. The standards deemphasize the use of institutional terms in dealing with the retarded and their problems. Under these standards, the residential facility will be integrated into the community and the general population as much as possible. The residents will use community resources such as schools, religious facilities, medical and other professional services, recreation facilities, stores, and employment facilities as extensively as possible. The facility will be designed and operated to help residents to move from structured, dehumanized, institutional living to a less structured, more individualized, and independent life. Facilities will emphasize groupings of program and residential units designed to meet residents' needs and integrated into, instead of segregated from, community life.

The second subchapter of Chapter I (sections 224 through 232) outlines general policies and practices under which a residential facility shall operate. It requires a facility to have generally available a written outline of the philosophy, objectives, and goals it is striving to achieve. The facility will also have a manual of policies and procedures describing what it is doing to achieve its objectives and goals. In addition, a statement of policies and procedures concerning the rights of residents will be required.

The facility is required to have a statement of policies and procedures that protect the financial interests of residents, manuals describing procedures in the major operating units of the facility, a summary of laws and regulations relevant to mental retardation and to the function of the facility, and a plan for a continuing management audit.

Public facilities will have documents describing their statutory basis of existence and the administration of the governmental department in which they operate. Private facilities will have documentation, including charters, constitutions and bylaws, and State licenses.

This subchapter describes the general duties of the governing body of a facility and the responsibilities of the chief executive officer and other persons responsible for the operation of the facility.

The subchapter also describes the general overall management, organization, and administration of the facility, including such matters as delegation of authority and responsibility, decisionmaking, proper utilization of staff, and effective channels of communication. There will be a plan for improvement of staff and services.

There will be provisions for effective staff and resident participation and communication, including use of staff meetings and standing committees. The facility will use a percentage of operating budget for self-renewal purposes. The findings of these activities will be disseminated to staff and consumer representatives. There will be a system of collection and recording of data describing the population of the facility.

The facility will have a publicly available description of services for residents. The facility will provide, by various means, for meaningful and extensive participation in the policymaking and operation of the facility by consumer representatives and the public.

The facility will establish an extensive public education and information program to develop understanding and acceptance of the mentally retarded and other developmentally disabled in all aspects of the community living.

Subchapter III of Chapter I (sections 233 through 239) describes standards for admission and release of mentally retarded residents of facilities. These provide that only those who can be helped by the facility's programs will be admitted, and that numbers of admissions will not exceed the facility's capacity and provisions for adequate programing.

Laws, regulations, and procedures for admission, readmission, and release will be summarized and available for distribution. The matter of legal incompetence will be separate from the matter of the need for residential services, and admission to a facility will not automatically imply legal incompetence.

Before admission, a resident must have a complete physical, emotional, social and cognitive evaluation. Service need for each resident will be defined without regard to the actual availability of all the desirable options. A retarded or other developmentally disabled person will be admitted to a facility only when it can be determined that this would be the best measure for him. When admission is not the best idea, but cannot be avoided, this must be acknowledged clearly and plans must be made to explore alternatives. The primary beneficiary of the admission to a facility must be clearly specified as the resident, his family, his community, society, and several of these. All admissions are to be regarded as temporary.

A medical evaluation by a physician will be made within a week of admission. Provision is made for continuing and regular evaluations of the resident and his progress in the facility.

Provision is made for physical inspection of the resident for signs of injury or disease prior to and following temporary or permanent release from the facility. Procedures are described for reporting on the resident's status at the time of permanent release or transfer from the facility.

In the event of serious illness or accident, impending death, or death, provision is made for informing next of kin or guardian, and the following of the wishes of that person concerning religious matters. In case of death of a resident, provision is made for autopsy, with permission, for suitable religious services and burial, if wished, and for informing coroner or medical examiner, in accordance with law.

Subchapter IV of Chapter I (sections 240 through 241) outlines the personnel policies a resident facility for the mentally retarded or other developmentally disabled must follow in order to comply with this law. It provides for a personnel director if warranted, for a written description of current personnel policies and practices to be available to all employees and for initial screening and regular evaluation of all personnel.

The subchapter provides that staffing should be sufficient so that the facility is not dependent upon residents or volunteers for the performance of productive services. It describes procedures under which residents can be involved in such services. The subchapter describes procedures for the establishment of an appropriate staff training program and the qualifications of the person responsible for this program. Also described are provisions for creating relations with nearby colleges and universities for advanced training of the facility's staff, for the use of facility resources for training and research by the colleges and universities, and for exchange of staff between the facility and the colleges and universities

Chapter II—Resident Living

The first subchapter of Chapter II (section 242) describes staff-resident relationships and activities. Staff of the facility's living units will devote their attention to the care and development of residents in the atmosphere of the living units as follows:

(1) By providing sufficient attention to each resident each day;

(2) By training residents in activities of daily living and in development of self-help and social skills;

(3) By providing a warm, family- or home-like environment;

(4) By not being diverted by housekeeping, clerical, and other nonresident-care activities; and

(5) By maintaining stability and consistent interpersonal relationships.

Living unit staff will participate with an interdisciplinary team in the overall care and development of the resident. Provision is made for evaluation and program plans for each resident to be available to living unit staff and to be reviewed regularly by the interdisciplinary team.

Activity schedules for each resident free of "dead time" of more than one hour and allowing for individual and group free activities will be available to living unit staff and implemented daily. Life in the living unit will resemble as much as is possible to cultural norm of nonretarded age peers. Residents will be assigned responsibilities in the living unit, and an effort will be made to enhance self-respect and to develop independent living skills. Provision must be made for appropriate out-of-bed and bedroom activities; for multiple handicapped and nonambulatory residents. Residents will have planned periods of time out doors and will be instructed on how to use freedom of movement both within and without the facility's grounds. Special events, such as birthdays, will be observed and provisions will be made for appropriate heterosexual interaction. Residents' view and opinions on matters concerning them will be elicited and considered. They will be instructed in the use of and will have appropriate access to communication processes, such as telephones and mail They will be permitted appropriate personal possessions and the possession and the use of money.

There will be provision for the recognition and management of behavioral problems in the living unit. There will be a written statement of appropriate policies and procedures for the control and discipline of residents. Corporal punishment will not be permitted and residents will not discipline other residents, except as part of an organized self-government program. Seclusion in a locked room will not be employed. Physical restraint will be used only when necessary to protect the resident from injury to himself or to others, and not for punishment, convenience of the staff, or as a substitute for program. Policies for the use of restraint will be in writing and will follow certain guidelines. Procedures are described for the appropriate use of mechanical supports, chemical restraints, and behavior modification programs.

The second subchapter of Chapter II (sections 243 and 244) describes the standards for food services in the resident facility. It provides that food services meet the needs of each resident and be professionally planned and nutritionally adequate. It provides for a written statement of goals, policies, and procedures of the facility's food services. A qualified nutritionist or dietitian will be employed or consulted regularly. The standards require that well-balanced meals be served to residents three times a day at appropriate intervals in dining rooms which are suitably designed and equipped. The food service of the facility, like all other services, must be designed and operated to meet the needs of the residents. Suitable supervision and systematic training in the development of appropriate eating skills will be provided. Provision must be made for cleaning equipment and for handwashing facilities.

Subchapter III (sections 245 through 247) of the second Chapter is concerned with provisions for clothing of the residents. Each resident will be provided an adequate supply of clothing comparable to the clothing worn in the community. Provision is made for the supplying of appropriate clothing to residents with special needs, such as the multiple handicapped, the nonambulatory, and the incontinent. Residents will be trained and encouraged to choose their own clothing, select their daily clothing, dress themselves, and maintain their clothing as independently as possible.

Subchapter IV (section 248) describes provisions for the health, hygiene, and grooming of residents. Residents will be trained to become as independent as possible in these matters of personal care, such as daily bathing, brushing teeth, etc. Staff assistance will be provided where appropriate, such as helping female residents in caring for menstrual needs, or in providing toilet training where needed.

Each living unit will have a properly adapted drinking unit and residents will be taught the proper use of such units.

Procedures will be established for regular weighing and height measurement of residents and for the maintenance of suitable records. Care of infectious and contagious diseases will conform to State and local health regulations. A physician will review regularly all orders prescribing bed rest and prohibition of outdoor activities. Such devices as dentures, eyeglasses, hearing aids, and braces will be furnished and maintained by appropriate specialists.

Subchapter V (section 249) describes standards for grouping and organization of living units. These living units will be small enough this law. It provides for a personnel director if warranted, for a written description of current personnel policies and practices to be available to all employees and for initial screening and regular evaluation of all personnel.

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Subchapter V (section 249) describes standards for grouping and organization of living units. These living units will be small enough to insure proper development of interpersonal relationships among residents and between residents and staff. A single unit, including sleeping, dining, and activity areas, should provide for the housing of not more than sixteen residents, and program groups within the unit should not exceed eight. Any deviation from either of these two size limitations would have to be justified on the basis of meeting program needs of the residents.

Residential units should house both male and female residents insofar as this conforms to prevailing cultural norms. Residents of widely varying ages, developmental levels, and social needs will not be housed together unless this is planned to promote growth and development. Residents will not be segregated solely on the basis of their handicaps. The living unit is not intended to be a self-contained program unit, but should be coordinated with activities residents engage in outside the living unit. Residents will be allowed free use of all living areas within the living unit, with due regard to privacy and personal possessions. Residents will have access to a private area where he can withdraw when not engaged in structured activities. Outdoor play and recreation areas will be accessible to all living units.

Subchapter VI (section 250) of Chapter II defines the policies and practices of the resident-living staff. It stipulates staff-resident ratios for each of the three shifts in a twenty-four hour day and for each type of living unit in the facility, so that there is adequate coverage of residents twenty-four hours a day, seven days a week.

Subchapter VII (section 251) outlines standards for design and equipage of living units, so that they are appropriate for the fostering of personal and social development, appropriate to the program, flexible enough to accommodate variations in program to meet changing needs, and such as to minimize noise and permit communication at normal conversation levels. The interior design of living units will simulate the functional arrangements of a home. The subchapter provides standards for minimum space requirements, and for the design and equipage of bedrooms, storage facilities, and toilet areas. It describes provisions for the safety, sanitation, and comfort of the residents by ventilation, temperature and humidity control, temperature of hot water, emergency lighting, and supply of clean linen.

Chapter 3—Professional and Special Programs and Services

This chapter (sections 252 through 254) outlines in great detail the various types of professional services that will be available to residents of a qualified residential facility for the mentally retarded. These professional and special programs and services will be provided in accordance with the residents' needs. They may be provided by programs within the facility or by arrangements between the facility and other agencies or persons. In order to promote normalization, all professional services will be rendered whenever possible in the community. The programs and services will meet standards for quality of service. Individuals providing the programs and services will be identified with appropriate professions, disciplines, or areas of service. Interdisciplinary teams for evaluating needs, planning individualized habilitation programs, and periodically reviewing residents' response to programs and revising programs accordingly, will be made up of persons drawn from or representing the relevant professions, disciplines, or service areas.

The standards in the subchapters describing each type of service are to be interpreted to mean that necessary services are to be provided efficiently and competently, without regard to the professional identifications of the persons providing them, unless only members of a single profession are qualified or legally authorized to perform the stated service. Therefore, services listed under the duties of one profession may be rendered by members of other professions who are equipped by training and experience to do so. Members of professional disciplines must work together in cooperation, coordinated, interdisciplinary fashion to achieve the objectives of the facility.

Programs and services and the pattern of staff organization and function within the facility will be focused upon serving the individual needs of residents and provide the following:

(1) Comprehensive diagnosis and evaluation of each resident;

(2) Design and implementation of an individualized habilitation program to meet the needs of each resident;

(3) Regular review, evaluation, and revision, of each individual program, as necessary;

(4) Freedom of movement of individuals from one level of achievement to another, as is warranted; and

(5) An array of those services that will enable each resident to develop to his maximum potential.

Each of the subchapters in Chapter 3 describes a specific type of service. Each subchapter describes the purposes for which the service is provided, describes the types of services that will be available, describes provisions for diagnosis and evaluation, defines qualifications of education, experience with the mentally retarded and other developmentally disabled, and professional certification of the personnel supervising and providing the services, and describes the physical necessities of space, equipment, and facilities for providing the services. The specific services are as follows:

(1) Dental Services, (secs. 255 and 256);
(2) Educational Services, (secs. 257 and 258);
(3) Food and Nutrition Services, (sec. 259);
(4) Library Services, (sec. 260);
(5) Medical Services, (sec. 261);
(6) Nursing Services, (sec. 262);
(7) Pharmacy Services, (sec. 263);
(8) Physical and Occupational Therapy Services, (sec. 264);
(9) Physiological Services, (sec. 265);
(10) Recreation Services, (sec. 266);
(11) Religious Services, (sec. 267);
(12) Social Services, (sec. 268);
(13) Speech Pathology and Audiology Services, (sec. 269);
(14) Vocational Rehabilitation Services, and (sec. 270); and
(15) Volunteer Services, (sec. 271).

Chapter 4—Record

The first subchapter (section 272) provides for the maintenance of adequate records for each resident. These records will be used to:

(1) Plan and evaluate each resident's habilitation program;

(2) Provide a means of communication among all persons contributing to each habilitation program;

(3) Furnish evidence of the resident's progress and response to program;

(4) Serve as a basis for review, study, and evaluation of the overall programs provided by the facility;

(5) Protect the legal rights of the residents, facility, and staff; and

(6) Provide data for use in research and education.

All records will be sufficiently detailed to meet these needs and will be legible, dated, and authenticated.

The second subchapter (section 273) lists types of information that will be included in the content of each resident's record, and provides that certain items be recorded at time of admission, within one month after admission, during residence, at the time of discharge from the facility, and in the case of death.

The third subchapter (section 274) describes procedures that will be followed to assure confidentiality of records.

The fourth subchapter (section 275) provides for the maintenance of an organized central record service for the collection and dissemination of information regarding residents.

Subchapter 5 (section 276) describes the types of statistical records that will be kept by the resident facility and provides that statistical data will be reported to appropriate Federal and other agencies as requested.

The sixth subchapter (section 277) describes standards for sufficiently qualified records personnel, supervised by a qualified individual, and provided with adequate space, facilities, equipment, and supplies.

Chapter 5—Research

This chapter (sections 278 through 281) provides standards for the encouragement of research, review of research proposals, conduct of research, and the reporting of research results.

Chapter 6—Safety and Sanitation

The first subchapter (section 282) describes safety requirements for resident facilities for the mentally retarded and other developmentally disabled persons. There is provision for adequate exits, exit doors and ramps, and for handrails on stairways. There must be documentation of compliance with State and local fire safety regulations. Each facility must have plans and procedures known to, and reviewed with, staff, for meeting potential emergencies and disasters. Evacuation drills will be held quarterly. Each facility will maintain an adequate active safety program. All buildings and facilities will be designed and constructed to be accessible to the physically handicapped and the nonambulatory. Paint used in the facility will be lead free and provision must be made for emergency auxiliary sources of heat.

The subchapter on sanitation (sec. 283) requires each facility to have documentation on compliance with sanitation, health, and environmental safety codes of State or local authorities. It requires adequate procedures for the holding, transferring, and disposal of waste and garbage. It provides for the availability of handwashing facilities and for the provision of insect screens where needed and for adequate janitorial equipment and storage space in each unit of the facility.

Chapter 7—Administration Support Services

The chapter (sec. 284) describes standards for the provision of adequate, modern administrative support to meet the needs of, and contribute to, program services for residents, and to facilitate attainment of the goals and objectives of the facility. It provides for a qualified administrator to supervise these services and for adequate office space, facilities, equipment, and supplies.

Part D—Standards for Community Facilities and Agencies; Programs for Mentally Retarded and Other Persons with Developmental Disabilities

Subpart 1—Individual support system

Section 285 (Case Finding).—Describes the meaning of "case finding" for the purposes of this part and requires facilities and agencies receiving Federal assistance under the act to establish written policies for such a program; designate a staff member to monitor and follow up the process, maintain evidence of its case finding activities in the areas of identifying persons in need, locating services, and assisting them in entering the service delivery system; alerting relevant agencies and individuals to the importance of early detection and of their role as case finders; coordinating such activities with those of relevant agencies and practitioners; and reaching out to meet expressed or unexpressed needs of the inarticulate.

Section 286 (Entry into the Service Delivery System).—Describes provisions for entry into the service delivery system, including a definition of the meaning of the term as used in this part.

Facilities and agencies receiving assistance under the act shall—

(1) Establish written policies regarding entry procedures, stipulating that persons are accepted for such services without regard to ethnic origin, sex, or ability to pay and without regard to the ability of the facility or agency to provide direct services;

(2) Obtain, provide or coordinate any services needed to facilitate entry, including assurances concerning arrangement of hours of operation to enable accessibility for total family units, accessibility of responsible staff members, transportation and home visits if necessary, and identification of available sources of funding for person and family;

(3) Service, at point of referral, any followup required to facilitate entry into the system, and such facility or agency shall obtain needed information to determine appropriate referrals, may use recorded information to make appropriate referrals, and shall have policies and procedures defining conditions of discharge and procedures for reentry if needed; and

(4) Insure annual evaluation of the entry procedure, such evaluation to include maintenance of a log of requests for information and other matters, the data from which log to be reviewed as a basis for planning, evaluating, and modifying the role of the facility or agency and as a part of the community coordinating process, that such data is shared with other agencies for appropriate use in such a way as does not reveal the identity of the individuals.

Section 287 (Follow-Along Services).—Defines the term "follow-along" as used in this part and requires affected facilities and agencies to provide follow-along services as needed; educate persons to seek such services when needed to enhance their independence; and provide each person served a specific point of contact in order to receive such services.

Each facility or agency, together with others, shall identify each person's follow-along agency, to promote efficient service and reduce duplication of effort. The person and his family must be informed of procedures for terminating and reentering such a program. The facility or agency must insure that the follow-along service assists with transition to a new service, as necessary; that the right to privacy is not violated; and that the person's status is recorded at least annually. A facility or agency providing such service may have access to appropriate information in the person's records.

Section 288 (Individual Program Plan).—Defines the individual program plan and requires affected facilities and agencies to insure that each person has an IPP. The section further describes what the IPP contains and how it will be used.

Section 289 (Program Coordination).—Defines program coordination as it is used in this part and requires that facilities and agencies receiving assistance under the act to insure that each person served is assigned a program coordinator to implement his IPP. The section further describes the duties and responsibilities of the program coordinator.

Section 290 (Protective Services).—Requires each State receiving assistance under the act to establish a system of continuing legal and social protection to monitor programs and assist persons in securing their rights and entitlements. Each State is directed to provide advice and guidance to persons and to actively intervene in social and legal processes, if necessary.

In providing the protective services function, each State must insure that—

(1) The protective services function is independent of the direct services;

(2) The services programs of each facility and agency are monitored to assure the receipt by each person of all entitled benefits, services, and rights;

(3) Services are provided in congregate living situations, as well as to those living alone or in families;

(4) Protective intervention is provided in cases of abuse or neglect;

(5) No right of a protected person may be abridged without due process;

(6) There is provision for periodic review of need to abridge rights, and for restoration if justified;

(7) Each facility and agency shall participate in education law enforcement agencies and local bar association concerning retardation and developmental disabilities and their special needs and shall make resources available to law enforcement officials if such persons are subject to arrest, questioning, or detention;

(8) Each facility and agency shall work with officials and courts in establishing a system for processing the developmentally disabled offender providing recognition of diminished responsibility and a means of avoiding unnecessary or undue confinement; and

(9) Each facility and agency shall instruct each person served concerning the law, how to obtain assistance if arrested, and shall provide those with communication problems with means of identification.

Section 291 (*Personal Advocacy Services*).—Define personal advocacy services and requires each facility and agency providing such services to—

(1) Identify persons needing advocates;

(2) Use volunteers as advocates;

(3) Assess ability of each of such advocates to perform competently;

(4) Provide assistance to advocates, and secure such legal and professional services as are needed;

(5) Mediate assumption of a legal role by an advocate;

(6) Evaluate performance of the advocate and the adequacy and effectiveness of the program at least quarterly;

(7) Have written procedures for terminating advocacy service;

(8) Solicit recommendations of advocates and persons respecting expansion or modification of advocacy services;

(9) Publicize the program; and

(10) Prepare and publish material to orient and train advocates.

The Section further describes the functions and responsibilities of a personal advocate.

Section 292 (*Guardianship Services*).—Describes guardianship services and requires each facility and agency assisted under the act to—

(1) Assist the person, family and court in determining need for guardianship;

(2) Assist the person, family, and court in assuring that a qualified guardian is available;

(3) If State law provides for corporate guardianship, assist in establishing procedures to eliminate conflicts of interest;

(4) Assist the guardian in understanding mental retardation and other developmental disabilities, and in fostering increased independence in the ward;

(5) Assist guardians to become more effective; and

(6) Work with the person, family, and court to insure due process.

In cases in which a guardian is compensated, the facility or agency must demonstrate efforts to insure that such compensation is in accordance with duties performed, rather than based on income or assets of the ward and that no person is denied services due to inadequate resources.

The agency shall assist the person or family, and the court in assuring that procedures are available for continuation or reestablishment of guardianship upon attainment of majority, or for the person who otherwise needs guardianship.

Further the agency shall assist the person, or family, and attorney in utilization of property management devices such as wills and trusts, educate the community concerning availability of such services, and if such services are not available, the facility or establishment shall establish them.

Subpart 2—Agency Service Components

Section 293 (*Purpose*).—Directs the program coordinator to assist in carrying out the IPP by selective use of available direct services.

Each facility and agency supplying services must make public a statement of the services it provides, and must demonstrate a willingness to modify services in relation to other services, and in response to community planning processes.

Each agency shall be evaluated on the basis of specific services it provides. Each of the service components described in this subpart shall be available within the service delivery system of each State.

Section 294 (Individual Assessment).—Defines individual assessment and requires each facility and agency receiving assistance under the Act to—

(1) Provide or procure assessment services, identify those areas in which it is competent to offer such services, and have written procedures for referring the person to other agencies for such services it does not provide;

(2) Include in each individual assessment, in providing data for the IPP, comprehensive assessments of development;

(3) Provide, through an interdisciplinary team, a comprehensive medical examination and other specialized assessments, where needed;

(4) Insure that all State licensure, certification, and registration laws regulating professional disciplines are observed;

(5) Assign responsibility for synthesizing, interpreting, and utilizing results of the various assessment components;

(6) Insure that the assessment is adapted to differing cultural backgrounds, languages, and ethnic origins;

(7) Insure that assessment data are recorded in terms that facilitate clear communication;

(8) Insure that each assessment identifies symptomatology and etiologies, where possible, of problems or disabilities; and

(9) Insure that the assessment process identifies all available alternatives for selection of needed services, establishes a focus of responsibility for such services, and that the process involves the person and family and that they are advised of the findings.

A preliminary individual assessment must be completed within 30 days of entry, and reassessment must be provided in significant intervals thereafter, and reports may be sent to other facilities or agencies providing services with written permission.

Section 295 (Attention to Health Needs).—Provides for attention to health needs, and directs each facility and agency receiving assistance to—

(1) Have procedures for early detection and remediation of special health needs;

(2) Provide or procure health assessment for each person, at regular intervals, at least annually;

(3) Provide for detection, diagnosis, and treatment of sensorimotor defects;

(4) Provide or procure corrective or prosthetic devices as required, along with provision for reevaluation and changes as needed and instruction to parents and staff in use and care;

(5) Provide or procure home health services;

(6) Insure that special health needs are met by generic community resources;

(7) Provide health supervision for disabled children that conforms to the latest edition of American Academy of Pediatric standards;

(8) Provide nutritional services;

(9) Provide services to develop functional oral systems;

(10) Have written policy regarding administration of medication used by persons served and written policy specifying medical emergency procedures;

(11) Insure that each person requiring medication receives appropriate supervision, including evaluation and monitoring and laboratory assessment;

(12) Have policies and procedures for dealing with infectious and contagious diseases;

(13) Include in inservice training programs instruction in handling of convulsive disorders, to be given to all personnel who work with affected persons; and

(14) Make available family planning and genetic counseling services.

Any facility or agency not providing specialized health services must refer persons and families to appropriate agencies and follow up such referrals.

Section 296 (Attention to Developmental Needs).—Provides for attention to developmental needs and directs that effective programs be based on a developmental model with certain specified assumptions regarding the nature of development. The section describes the objective of services in developmental needs. It further directs each facility and agency to make available attention to developmental needs to every person served. Basic objectives of such a program are described.

Each facility and agency receiving assistance shall—

(1) Assist in initiating developmental program beginning in infancy continuing throughout the lifespan;

(2) Insure that its program is determined by individual needs and not contingent on age or time restrictions;

(3) Implement in each person's IPP the progressive steps and goals to be attained;

(4) Define responsibilities of both agency and family as they affect attainment of objectives, and the communication mechanism;

(5) Provide or procure formal education and training services at all levels;

(6) Insure that the objectives of education and training programs are related to long-range goals;

(7) Insure that education and training programs meet established State standards and that instructional techniques, physical settings, and materials are appropriate;

(8) Identify programs and services available from other sources;

(9) Document the person's participation in selection of alternatives relating to activities of daily living;

(10) Prohibit the use of corporal punishment, verbal abuse, and seclusion; and

(11) Have a written policy defining use of behavior modification programs, staff members who may authorize their use, and mechanism for monitoring and controlling their use.

Persons shall not discipline other persons, except as part of an organized self-government program conducted in accordance with written policy.

Section 297 (Sensorimotor Development).—Defines motor development and describes the type of sensorimotor development program each facility and agency must provide, including inclusion in each IPP objectives relating to such development, specific programs directed to nonambulatory individuals, individually prescribed sensorimotor development activities, direct or consulting services from professionally qualified persons, and functional integration of sensorimotor activities and therapeutic interventions in other programs that it provides.

Section 298 (Communicative Development).—Defines communicative development and describes the type of program each facility and agency must provide in communicative development—inclusion in the IPP, appropriate training, specialized services, opportunities for use of functional skills in daily living, and instruction in the availability and use of all forms of communications media.

Section 299 (Social Development).—Defines social development and describes the type of program each facility and agency must provide in such development—inclusion in the IPP, development of culturally normative behavior, activities for interaction outside the training program, programs in grooming and safety, a program for the family to encourage independent functioning, and counsel for person and family concerning conflicts and how to handle them.

Section 299A (Affective Development).—Defines affective development and describes the type of program each facility and agency must provide in this area of development—inclusion in the IPP, development of expression of appropriate emotional behaviors, the proper environment conducive to development of positive feelings, development and enhancement of self-concept, a variety of experiences to develop interest and appreciative of esthetics, and specific training objectives for changing maladaptive behavior into more adaptive behavior.

Section 299B (Cognitive Development).—Defines cognitive development and describes the type of program each facility and agency must provide in such development—inclusion in the IPP, help for parents in fostering cognitive development, initial activities in development of cognitive skills, opportunities for alternatives leading to independent action.

Section 299C (Services to Support Employment and Work).—Describes required services to support employment and work. Each facility and agency shall—

(1) Include work objectives in each IPP;

(2) Provide opportunities and alternatives in vocational training and retraining;

(3) Integrate work and employment program with the community;

(4) Provide materials for productive work at the person's place of residence, when in his best interest;

(5) Provide support in more constructive use of leisure time;

(6) Maintain contact with advocate, guardian, family or others to evaluate work expectations and performance;

(7) Maintain documentary evidence of production level earning rate;

(8) Insure that persons who are paid for productive work are provided other appropriate benefits; and

(9) Utilize definitive time study procedures and competitive bidding practices.

Section 229D (Recreation and Leisure).—Defines recreation and describes types of recreation and leisure activities that each facility and agency shall provide—

(1) Activities that are designed to allow the person to choose whether or not to participate and to choose the type of activity; develop skills and interests leading to effective use of leisure time, provide opportunities for success, experiences that develop social interaction, activities that promote health, and individualized therapeutic activities for alleviation of disabilities and prevention of regression;

(2) Planning and organization of recreation programs and activities including specific objectives for each person, based on his IPP, assessments of abilities and performance level, to determine appropriate types of recreation activities, grouping according to wishes and abilities, selection of method of presentation according to abilities, communication and coordination with other agencies for wider opportunities, participation with nondisabled persons, and parent and family education concerning leisure time activities;

(3) Recreation activities to persons served by other agencies, and to others not served by any direct program, through daytime activities;

(4) When generic community programs are not available to the disabled, initiate action to make such programs available;

(5) Insure that recreation programs are available to severely and multiple disabled persons; and

(6) Keep the population that it serves informed of all recreation opportunities.

Section 299E (Family Related Services).—Defines family related services and directs that all services provided to persons must include consideration and involvement of his family, and the special needs of the family must be recognized. Family members must be recognized. Family members must be assisted in understanding the impact of disability and the person and their relationships with him, and to mobilize their strengths in coping with the disability. Instruction in facilitating development of the person, including training in management techniques, shall be provided.

Section 299F (Home Training Services).—Defines home training services and provides that each facility and agency shall—

(1) Provide home training services through a home trainer who shall—develop with the family a program that is a component of the IPP and is carried out in the home; instruct the family how to carry out the program; provide for family use of specialized materials, provide information of developmental disabilities and developmental patterns, develop methods of assessing assets, liabilities, and level of performance; assist person and family in incorporating various therapies into the daily regime; coordinate the person's activities with services delivered by others; demonstrate special procedures; help adapt home equipment; help the family make or identify resources for obtaining specialized equipment; assist with special clothing adaptations; and provide continuing support and assistance;

(2) Coordinate its efforts with other agencies and services involved with the person and family and if home training services are not available the facility or agency shall initiate them.

Section 229G (*Homemaker Services*).—Defines homemaker services and directs each facility and agency to insure that—

(1) Homemaker services shall be available when needed;

(2) The homemakers shall teach appropriate techniques of home management;

(3) The homemaker's special skills shall be sufficient to meet a variety of family emergencies, including relief in a crisis;

(4) Evaluation of the family's needs are to be made prior to placement of a homemaker, and shall continue after such placement;

(5) The homemaker shall be apprised of the family situation prior to entering the home;

(6) The homemaker shall be prepared to assist with the training program of the person, so that he may remain in the home; and

(7) If homemaker services are not available, the agency shall initiate them.

Section 299H (*Respite Care*).—Defines respite care and describes the type of respite care program each facility and agency shall provide—day and night respite care service; identification of other agencies that provide such care; written plan for retirement, selection, training, and evaluation of persons providing such care; monitoring of such services to insure continuity with normal living patterns; and initiation of such services when not available.

Section 299I (*Sitter Services*).—Defines sitter services and describes the type of sitter services program each facility and agency must provide—sitter services available on hourly or weekly schedules; written plan for recruitment, selection, training, and evaluation of sitters; insurance that sitter personnel have specialized training and experience in the management of disabled persons; if the agency does not provide sitter services, identify sources that do; and if sitter services are not available, initiation of them.

Section 299J (*Family Education Services*).—Defines family education services and directs each facility and agency to—

(1) Provide family education opportunities on a regularly scheduled basis and as family needs arise;

(2) Insure that family members have the opportunity to observe the person in a service setting;

(3) Insure that planned conferences between staff and families are held on a regular basis;

(4) Provide parent-to-parent counseling for newly identified parents and in times of crisis;

(5) Conduct group meeting for siblings of the disabled;

(6) Maintain a resource library available for use by the family on the broad subject of mental retardation and other development disabilities; and

(7) Have a planned program for mobilizing and utilizing parent leadership skills.

Section 299K (*Attention to Needs for Mobility*).—Defines mobility and attention to needs for mobility and requires each facility and agency to—

(1) Provide services to increase mobility of disabled persons as specified in their individual plans;

(2) Promote maximum safety in the use of all mobility devices and procedures, including inspection at least quarterly of all equipment;

(3) Actively strive to eliminate architectural barriers, modify equipment and facilities, insuring the use of elevators where indicated, and the accessibility of restrooms, water fountains, and other facilities;

(4) Shall make driver education available to those who are capable of learning to drive;

(5) Promote or help establish generic community transportation services usable by disabled persons;

(6) Assist persons in securing transportation enabling them to have access to needed programs and services, including transportation after hours and on weekends;

(7) Insure that the transportation system is licensed and inspected, that drivers are trained and licensed, that it is adequately insured, and is adapted to the special needs of the persons; and

(8) Compile data concerning persons denied or excluded from services because of their unique mobility needs.

Subpart 3—Community Organization

Section 299L (Purpose).—Directs the service delivery system to be so organized that each person has services available at time of need, and in close proximity to his home, with one agency or facility responsible for implementing a systematic method of collecting data useful for planning and coordinating activities, and making available to other facilities and agencies current information on the resources available in the community for serving mentally retarded and other developmentally disabled persons.

Section 299M (Resource Information and Data Documentation Services).—Directs the agency identified in sec. 299L to establish a resource information service to compile and disseminate current and complete listing of all appropriate resources, referral procedures, and other pertinent information and a data documentation service to collect and disseminate data that is useful for planning and coordinating activities.

A single agency within each community shall provide a centralized resource information and data documentation service.

Each community whose facilities and agencies receive assistance under the act shall—

(1) Maintain a resource information service which will be an easily identifiable point of contact for professionals and agencies seeking assistance, and which shall—have directories of local resources and regional and State agencies and facilities; have standing procedures for handling information concerning resources and services; have written policies on standards for services to which referrals are made; have followups on referrals; analyze referral reports; disseminate information about activities; work with other agencies and facilities to improve resource information and referral services; make materials available for inservice training and community education; and provide consultation services to support community organization activities;

(2) Maintain a data documentation service to coordinate its activities with those of other such agencies, to minimize duplication of effort and encourage the use of standardized reporting systems and which shall—collect data at least yearly from all agencies and facilities in the system; provide consultation to local agencies in the design of reporting systems; disseminate data for community education and

social action programs; regularly categorize the reasons that persons are rejected for service; and report this information to planning and coordinating bodies as a means of stimulating program modification and development;

(3) Work with other agencies in the system to develop a continuum of services to meet all the needs of the disabled; and

(4) Participate in a regular review of the service delivery system including an analysis of—design of system and agency approach to problem solving; point efforts to resolve problems in providing services; need for integration of ongoing programs within the system, identification and resolution of conflicting policies and practices, identification and resolution of unnecessary duplication or uneven distribution of services; need for simplification and combination of administrative, operational, and funding procedures; coordination of data collection and use of data to study characteristics and needs of the community; and development of standards for personnel selection and performance; and for program evaluation.

Section 299N (Coordination).—Defines coordination and requires each facility and agency to carry out certain coordination activities—a written statement clearly defining its role and function within the service delivery system; a directory of all other resources within the system; cooperative agreements with other components of the system; and procedures for coordination with other components of the system.

Section 299O (Agency Advocacy).—Defines agency advocacy and requires each facility and agency to carry out certain agency advocacy activities—participating where appropriate with a coalition of other agencies in developing a plan for agency advocacy; identifying problems, methods for resolving them, and strategies for resolving legal or legislative problems; making its findings and recommendations known to the public and appropriate governmental bodies; and encouraging and demonstrating the participation of persons served, their families, and their advocates.

Section 299P (Community Education and Involvement).—Defines community education and involvement and requires each facility and agency to—

(1) Conduct ongoing community education programs;

(2) Establish a point for collecting and disseminating information, with procedures for dissemination during a crisis;

(3) Participate in community awareness of the causes of mental retardation and other developmental disabilities;

(4) Educate general public about available community programs and unmet needs;

(5) Educate the community by a variety of techniques;

(6) Identify, and conduct information sessions for special audiences;

(7) Conduct educational sessions for public and private officials on the advantages of normalized living arrangements for disabled persons, to promote zoning ordinances and licensing standards that promote normalization; and

(8) Promote community involvement by a variety of methods.

Section 299Q (Prevention).—Defines prevention and requires each facility and agency to—

(1) Maintain current information concerning available preventive services;

(2) Insure that preventive services are readily accessible, regardless of ability to pay;

(3) Make provisions for providing or procuring preventive services for all conditions known to entail risk;

(4) Have provisions for ongoing child health programs;

(5) Insure that highly specialized preventive services are available, at least on a regional basis;

(6) Insure that services are offered to those unaware of their problems, or unaccustomed to asking for help;

(7) Include current information concerning prevention in orientation and inservice training programs for staff;

(8) Participate with a coalition of other agencies in implementing communitywide preventive activities;

(9) Provide opportunities for young people and parents to learn about child development and rearing;

(10) Undertake preventive activities in environmental areas;

(11) Undertake biomedical preventive activities; and

(12) Undertake special preventive services including genetic screening and counseling and accident prevention and safety programs.

Section 299R (*Manpower Development*).—Defines manpower development and requires each facility and agency to cooperate with other agencies to assure availability of adequate present and future supply of qualified personnel through such activities as:

(1) Working relationships between agencies and nearby colleges and universities to make courses, seminars, and workshops available to staff; make agency resources available for training and research; permit exchange of staff between agencies and colleges or universities for teaching, research, and consultation; allow students to visit and observe agency programs, and to participate in field placement supervised by agency staff;

(2) Working relationships with other nearby manpower training centers to provide follow-up and feedback regarding effectiveness of programs, identify new manpower training needs, and evaluate manpower training programs yearly; and

(3) Participating in training programs conducted by university affiliated facilities, where available.

Section 299S (*Volunteer Services*).—Defines volunteer services and requires each agency and facility to—

(1) Use volunteers to support and supplement paid staff activities;

(2) Follow established policies concerning use of volunteers;

(3) Insure that volunteer participation is open to all;

(4) Insure that volunteer participation complies with all State and Federal laws;

(5) Insure that such services are available to all;

(6) Designate a staff member to be responsible for conducting the volunteer services program;

(7) Maintain accurate records concerning such services; and

(8) Provide a volunteer services advisory committee.

Subpart 4—Program Evaluation

Section 299T (*Program Evaluation*).—Defines program evaluation and requires each agency or agency to—

(1) Have a written statement of its goals and objectives;

(2) Evaluate its performance against stated goals and objectives periodically, and at least annually;

(3) Provide for staff, persons, and family involvement in the evaluation process;

(4) Measure effectiveness of programs and services in terms of progress of persons served;

(5) Have procedures for monitoring of the person's progress toward objectives in his IPP;

(6) Provide for review and modification of objectives, policies, and practices in the evaluation process;

(7) Where cooperative efforts among agencies exist, provide that services are evaluated cooperatively;

(8) Have evidence of cooperative efforts with other agencies to develop a continuum of services to meet all needs;

(9) Insure that the number of persons served is consistent with needs for service;

(10) Insure that appropriate alternative and options exist to meet varied needs; and

(11) Provide funding sources with evidence of accomplishments and shortcomings.

Subpart 5—Research and Research Utilization

Section 299U (*Research and Utilization*).—Defines research and research utilization and requires each agency and facility to—

(1) Indicate in its statement of purposes whether it will engage in research activities;

(2) Provide written policy concerning purpose and conduct of all research;

(3) Consult staff members regarding development of research efforts and make available resources and other assistance and insure that liaison is provided with each project conducted by outside investigators;

(4) Establish an interdisciplinary research committee to review all proposed studies;

(5) Establish a human rights committee to assure the protection of rights and welfare of subjects and to insure that informed consent is obtained;

(6) Provide adequate procedures for obtaining informed consent;

(7) Insure that written or oral agreement by the subject includes no exculpatory language to waive legal rights or release the agency from liability;

(8) Insure that the individual conducting research involving human subjects is affiliated with or sponsored by an agency that shares responsibility for protection of the subjects;

(9) Provide guidelines to deal with emergencies;

(10) Insure that investigators and others involved in research adhere to ethical standards and obtain or have access to record of informed consent;

(11) Insure that the principal investigator of each completed project communicates with staff the purpose, nature, outcome, and possible implications of the research and that outside researchers have some obligations relative to staff information and feedback as do agency staff;

(12) Insure that copies of research reports shall be maintained in the agency and that the agency assists in disseminating results of

research to other units of the delivery system, assuring anonymity of persons and parents;

(13) Have a mechanism to review findings external to the agency, and to implement such findings to improve quality of services provided; and

(14) Cooperate with research and research training programs conducted by colleges, universities, and research agencies, or by other qualified investigators.

Subpart 6—Records

Section 299V (Records).—Defines record and states that the establishment and maintenance of a functional records system shall be an essential activity of each community service program, such records to document services provided, action taken, contacts with those rejected for service or referred to other agencies, and to be available to parents and persons served on demand and to record only objective data observable behaviors.

Each facility and agency shall—

(1) Insure that an adequate record is maintained for each person;

(2) Insure that all pertinent information is incorporated in the record in sufficient detail and clarity;

(3) Assist the family in documenting its role in implementing the IPP;

(4) Insure that the record shall be available to the family and the person on demand;

(5) Insure that certain specified information is obtained and entered in the person's record at time of entry to the program;

(6) Insure that within 3 months of initial contact, other specified data are entered in the person's record;

(7) Insure that record entries during the period of service shall include certain specified information;

(8) Insure that the discharge summary shall be entered in the record within 7 days after termination of services, to include certain specified information;

(9) Insure that all information contained in the record, including that contained in an automated data bank, shall be privileged and confidential, including certain specified assurances;

(10) Maintain an organized record system for collection and dissemination of information regarding persons served, to be compatible with an existing community or State system;

(11) Insure that statistical information includes at least certain specified types of statistical data; and

(12) Insure that data is reported to appropriate community, State, and Federal agencies as required.

Subpart 7—Administration

Section 299W (Philosophy, Policies, and Practices).—Defines administration and requires each agency or facility to—

(1) Have a written statement of philosophy stipulating mission, purpose, and role, such statement to be distributed to staff and available to others;

(2) Insure that the ultimate aim of the agency is to foster behaviors maximizing human quality, increase complexity of behavior, and enhance ability to cope with the environment, and in so doing to utilize

normalization and the least restrictive alternatives consistent with needs and objectives;

(3) Facilitate integration by making generic services accessible when appropriate;

(4) Insure that the agency and its service delivery unit shall be located within, and be accessible to, the population served;

(5) Regulate services and resources to those of other agencies in its community;

(6) Have a written statement of policies and procedures concerning the rights of the consumer population that contains certain specified requirements;

(7) Have a written statement of policies and procedures to protect the financial interests of its consumer population;

(8) Have evidence that views and opinions of the person on matters concerning him are elicited and considered unless he is unable to communicate;

(9) Have a waiting list policy and procedure that provides for interim services and assisted referral services;

(10) Require that services provided by other agencies meet standards for quality;

(11) Insure that residential services provided comply with standards under this title;

(12) Have documentary evidence of its source of operating authority;

(13) Insure that the governing body shall exercise general direction and establish policies concerning operation of the agency and welfare of the persons served;

(14) Insure that the governing body establishes a job description for the chief executive officer position, including appropriate qualifications;

(15) Insure that a chief executive officer so qualified is employed and delegates to him authority and responsibility for management of the affairs of the agency in accordance with established policy;

(16) Provide for meaningful and extensive consumer and public participation in development of agency policies, through certain specified means;

(17) Be administered and operated in accordance with sound management principles;

(18) Have a policies and procedures manual describing methods, forms, processes, and sequences of events utilized to achieve objectives and goals;

(19) Have copies of laws, rules, and regulations relevant to its functions;

(20) Have implemented a plan for a continuing management audit;

(21) Have a written plan for improving quality of staff and services reflecting staff responsibilities in establishing and maintaining standards for services;

(22) Provide for effective staff and consumer participation and communication in certain specified ways;

(23) Have a sufficient number of qualified and trained personnel to conduct programs in accordance with standards in this title;

(24) Provide space, equipment, and environment that is appropriate and adequate for conducting its program;

(25) Insure that funds are budgeted and spent in accordance with budgeting principles and procedures, as specified;

(26) Insure that those acting on the agency's budget requests have knowledge of operations and needs, obtained by visitation and observation;

(27) Insure a full annual audit of fiscal activities;

(28) Insure that fiscal reports are prepared and communicated annually;

(29) Insure that there are written purchasing policies;

(30) Have adequate insurance coverage;

(31) Provide that charges for service have a written schedule of rates and charge policies available to all;

(32) Insure that fundraising activities comply with laws and ethical practices;

(33) Insure that adequate services for personnel administration shall be provided by appropriate means;

(34) Provide a statement of personnel policies and practices that contains certain specified insurances;

(35) Develop with each consultant and staff member a performance description of assigned duties, to include certain specified types of information;

(36) Provide a written statement of the agency's policies and procedures for handling cases of neglect and abuse;

(37) Staff shall be sufficient so that the agency is not dependent on consumer population or volunteers. There shall be a written policy protecting persons from exploitation when engaged in training and productive work, and persons who function as staff shall be treated and paid as staff;

(38) Insure that a staff development program is provided including certain specified orientation and training programs;

(39) Insure the provision for staff to improve their competencies by certain specified opportunities;

(40) If the agency provides food services, provide a written statement of goals, policies, and procedures that contain certain specified types of information;

(41) Persons with special eating disabilities are provided with diagnosis remediation of their problems;

(42) Provide when food services are not directed by a nutritionist of dietitian, that regular consultation with one of these is documented;

(43) Provide for posting and filing of the daily menu;

(44) Insure that requirements of the National Fire Protection Association Life Sefety Code shall be met, with specific references to certain specified provisions;

(45) Insure that records document compliance with sanitation, health, and environmental safety codes of the State or local authority with primary jurisdiction are met;

(46) Have evidence that it is aware of the provisions of OSHA of 1970;

(47) Insure that insurance company written inspection reports and records are kept on file;

(48) Have a written staff organization plan and written procedures for meeting potential emergencies and disasters;

(49) Insure that adequate evacuation drills are held;

(50) Insure that all buildings and outdoor recreation facilities constructed after December 31, 1974, are accessible to, and usable by, the nonambulatory, and meet all specifications for making buildings accessible to the physically handicapped; and

(51) Use lead free paint and remove or cover old paint and plaster containing lead.

TABULATION OF VOTES IN COMMITTEE

Pursuant to section 133(b) of the Legislative Reorganization Act of 1946, as amended, the following is a tabulation of rollcall votes in Committee: S. 3378 was unanimously ordered favorably reported by rollcall vote.

COST ESTIMATE PURSUANT TO SECTION 252 OF THE LEGISLATIVE REORGANIZATION ACT OF 1970

In accordance with section 252 (a) of the Legislative Reorganization Act of 1970 (P.L. 91-510), the Committee estimates that if all funds authorized were appropriated during fiscal year 1975 and the succeeding fiscal years, the five-year costs occasioned by S. 462, as reported, would be as follows:

AUTHORIZATION OF APPROPRIATIONS, S. 462

	Fiscal year—				
	1975	1976	1977	1978	1979
TITLE I					
Pt. A:					
Renovation and construction	6,500,000	6,500,000	6,500,000	6,500,000	6,500,000
Demonstration, training, and operational grants	25,000,000	25,000,000	25,000,000	25,000,000	25,000,000
Pt. B:					
Planning, provision of services and construction and operation of facilities	50,000,000	85,000,000	95,000,000	100,000,000	110,000,000
National council	100,000	100,000	100,000	100,000	100,000
Evaluation	1,000,000	1,000,000			
Special projects	17,500,000	20,000,000	22,500,000	25,000,000	27,500,000
TITLE II					
National council	([1] [2])	([1] [2])	([1] [2])	([1] [2])	([1] [2])
Assistance to States	([1] [3])	([1] [3])	([1] [3])	([1] [3])	([1] [3])
Evaluation	1,000,000	1,000,000			
Total	101,100,000	138,600,000	149,100,000	156,600,000	169,100,00

[1] Such sums.

[2] Standard estimate of amount needed by advisory councils is $100,000 per fiscal year.

[3] The committee estimates that in the first fiscal year $1,000,000 for technical assistance to the States, and such sums as may become necessary to assist the States in fiscal years thereafter.

Note: 5-yr total of authorizations: $714,500,000.

CHANGES IN EXISTING LAW

In compliance with paragraph 4 of the rule XXIX of the Standing Rules of the Senate, changes in existing law made by the bill, as reported, are shown as follows (existing law proposed to be omitted is enclosed in black brackets, new matter is printed in italic, existing law in which no change is proposed is shown in roman):

Mental Retardation Facilities and Community Health Centers Construction Act of 1963, as Amended

TITLE I—SERVICES AND FACILITIES FOR THE MENTALLY RETARDED AND PERSONS WITH OTHER DEVELOPMENTAL DISABILITIES

SHORT TITLE

Sec. 100. This title may be cited as the "Developmental Disabilities Services and Facilities Construction Act".

* * * * * * *

[Part B—Construction, Demonstration, and Training Grants for University-Affiliated Facilities for Persons With Developmental Disabilities

[AUTHORIZATION OF APPROPRIATIONS

[Sec. 121. (a) For the purpose of assisting in the construction (and the planning for the construction) of facilities which will aid in demonstrating provision of specialized services for the diagnosis and treatment, education, training, or care of persons with developmental disabilities or in the interdisciplinary training of physicians and other specialized personnel needed for research, diagnosis and treatment, education, training, or care of persons with developmental disabilities, including research incidental or related to any of the foregoing activities, there are authorized to be appropriated $5,000,000 for the fiscal year ending June 30, 1964, $7,500,000 or the fiscal year ending June 30, 1965, $10,000,000 each for the fiscal year ending June 30, 1966, the fiscal year ending June 30, 1967, and the fiscal year ending June 30, 1968, and $20,000,000 for each of the next five fiscal years through the fiscal year ending June 30, 1973. Except as provided in subsection (b), the sums so appropriated shall be used for project grants for construction of public and other nonprofit facilities for persons with developmental disabilities which are associated with a college or university.

[(b) (1) Of the sums appropriated pursuant to subsection (a) for any fiscal year, beginning with the fiscal year ending June 30, 1968, an amount equal to 2 per centum thereof (or smaller amounts as the Secretary may determine to be appropriate) shall be available to the Secretary for the purpose of making grants to cover not to exceed 75 per centum of the costs of the planning of projects with respect to the construction of which applications for grants may be made under this part. Not more than $25,000 shall be granted under this subsection with respect to any project.

[(2) Planning grants under this subsection shall be made by the Secretary to such applicants and upon such terms and conditions as he shall by regulation prescribe. Payment of grants under this subsection shall be made in advance or by the way of reimbursement, as the Secretary may determine.

[(3) Whenever, in the succeeding provisions of this part, the term "grant", "grants", or "funds" is employed, such term shall be deemed not to include any grant under this subsection or any of the funds of any such grant.

[DEMONSTRATION AND TRAINING GRANTS

[SEC. 122. (a) For the purposes of assisting institutions of higher education to contribute more effectively to the solution of complex health, education, and social problems of children and adults suffering from developmental disabilities, the Secretary may, in accordance with the provisions of this part, make grants to cover costs of administering and operating demonstration facilities and interdisciplinary training programs for personnel needed to render specialized services to persons with developmental disabilities, including established disciplines as well as new kinds of training to meet critical shortages in the care of persons with developmental disabilities.

[(b) For the purpose of making grants under this section, there are authorized to be appropriated $15,000,000 for the fiscal year ending June 30, 1971; $17,000,000 for the fiscal year ending June 30, 1972; and $20,000,000 for the fiscal year ending June 3, 1973.

[APPLICATIONS

[SEC. 123. (a) Applications for grants under this part with respect to the construction of any facility may be approved by the Secretary only if the application contains or is supported by reasonable assurances that—

[(1) the facility will be associated, to the extent prescribed in regulations of the Secretary, with a college or university hospital (including affiliated hospitals), or with such other part of a college or university as the Secretary may find appropriate in the light of the purposes of this part;

[(2) the plans and specifications are in accord with regulations prescribed by the Secretary under section 139(d);

[(3) title to the site for the project is or will be vested in one or more of the agencies or institutions filing the application or in a public or other nonprofit agency or institution which is to operate the facility;

[(4) adequate financial support will be available for construction of the project and for its maintenance and operation when completed; and

[(5) all laborers and mechanics employed by contractors or subcontractors in the performance of work on construction of the project will be paid wages at rates not less than those prevailing on similar construction in the locality as determined by the Secretary of Labor in accordance with the Davis-Bacon Act, as amended (40 U.S.C. 276a—276a-5); and the Secretary of Labor shall have with respect to the labor standards specified in this paragraph the authority and functions set forth in Reorganization Plan Numbered 14 of 1950 (15 F.R. 3176; 5 U.S.C. 133z-15) and section 2 of the Act of June 13, 1934, as amended (40 U.S.C. 276c).

[(b) Applications for demonstration and training grants under this part may be approved by the Secretary only if the applicant is a college or university operating a facility of the type described in section 121, or is a public or nonprofit private agency or organization operating such a facility. In considering applications for such grants, the Secretary shall give priority to any application which shows that the applicant has made arrangements, in accordance with regulations of the Secretary, for a junior college to participate in the programs for which the application is made.

[AMOUNT OF GRANTS; PAYMENTS

[SEC. 124. (a) The total of the grants with respect to any project under this part may not exceed 75 per centum of the necessary cost thereof as determined by the Secretary.

[(b) Payments of grants under this part shall be made in advance or by way of reimbursement, and on such conditions as the Secretary may determine.

[RECOVERY

[SEC. 125. If any facility with respect to which construction funds have been paid under this part shall, at any time within twenty years after the completion of construction—

[(1) be sold or transferred to any person, agency, or organization which is not qualified to file an application under this part, or

[(2) cease to be a public or other nonprofit facility for persons with developmental disabilities, unless the Secretary determines, in accordance with regulations, that there is good cause for releasing the applicant or other owner from the obligation to continue such facility as a public or other nonprofit facility for persons with developmental disabilities,

the United States shall be entitled to recover from either the transferor or the transferee (or, in the case of a facility which has ceased to be a public or other nonprofit facility for persons with developmental disabilities, from the owners thereof) an amount bearing the same ratio to the then value (as determined by the agreement of the parties or by action brought in the district court of the United States for the district in which the facility is situated) of so much of the facility as constituted an approved project or projects, as the amount of the Federal participation bore to the cost of the construction of such project or projects.

[NONDUPLICATION OF GRANTS

[SEC. 126. No grant may be made after January 1, 1964, under any provision of the Public Health Service Act, for any of the fiscal years in the period beginning July 1, 1965, and ending June 30, 1970, for construction of any facility for persons with developmental disabilities described in this part unless the Secretary determines that funds are not available under this part to make a grant for the construction of such facility.

[MAINTENANCE OF EFFORT

[SEC. 127. Applications for grants under this part may be approved by the Secretary only if the application contains or is supported by reasonable assurances that the grants will not result in any decrease in the level of State, local, and other non-Federal funds for services for persons with developmental disabilities and training of persons to provide such services which would (except for such grant) be available to the applicant, but that such grants will be used to supplement, and, to the extent practicable, to increase the level of such funds.

[PART C—GRANTS FOR PLANNING, PROVISION OF SERVICES, AND CONSTRUCTION AND OPERATION OF FACILITIES FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

[DECLARATION OF PURPOSE

[SEC. 130. The purpose of this part is to authorize—

[(a) grants to assist the several States in developing and implementing a comprehensive and continuing plan for meeting the current and future needs for services to persons with developmental disabilities;

[(b) grants to assist public or nonprofit private agencies in the construction of facilities for the provision of services to persons with developmental disabilities, including facilities for any of the purposes stated in this section;

[(c) grants for provision of services to persons with developmental disabilities, including costs of operation, staffing, and maintenance of facilities for persons with developmental disabilities;

[(d) grants for State or local planning, administration, or technical assistance relating to services and facilities for persons with developmental disabilities;

[(e) grants for training of specialized personnel needed for the provision of services for persons with developmental disabilities, or research related thereto; and

[(f) grants for developing or demonstrating new or improved techniques for the provisions of services for persons with developmental disabilities.

[AUTHORIZATION OF APPROPRIATIONS

[SEC. 131. In order to make the grants to carry out the purposes of section 130, there are authorized to be appropriated $60,000,000 for the fiscal year ending June 30, 1971, $105,000,000 for the fiscal year ending June 30, 1972, and $130,000,000 for the fiscal year ending June 30, 1973.

[STATE ALLOTMENTS

[SEC. 132. (a)(1) From the sums appropriated to carry out the purposes of section 130 for each fiscal year, other than amounts reserved by the Secretary for projects under subsection (e), the several States shall be entitled to allotments determined, in accordance with regulations, on the basis of (A) the population, (B) the extent of need for services and facilities for persons with developmental disabilities, and (C) the financial need, of the respective States; except that the allotment of any State (other than the Virgin Islands, American Samoa, Guam, and the Trust Territory of the Pacific Islands) for any such fiscal year shall not be less than $100,000 plus, if such fiscal year is later than the fiscal year ending June 30, 1971, and if the sums so appropriated for such fiscal year exceed the amount authorized to be appropriated to carry out such purposes for the fiscal year ending June 30, 1971, an amount which bears the same ratio to $100,000 as the difference between the amount so appropriated and the amount authorized to be appropriated for the fiscal year ending June 30, 1971, bears to the amount authorized to be appropriated for the fiscal year ending June 30, 1971.

[(2) In determining, for purposes of paragraph (1), the extent of need in any State for services and facilities for persons with developmental disabilities, the Secretary shall take into account the scope and extent of the services specified, pursuant to section 134(b)(5), in the State plan of such State approved under this part.

[(3) Sums allotted to a State for a fiscal year and designated by it for construction and remaining unobligated at the end of such year shall remain available to such State for such purpose for the next fiscal year (and for such year only), in addition to the sums allotted to such State for such next fiscal year: *Provided*, That if the maximum amount which may be specified pursuant to section 134(b)(15) for a year plus any part of the amount so specified pursuant thereto for the preceding fiscal year and remaining unobligated at the end thereof is not sufficient to pay the Federal share of the cost of construction of a specific facility included in the construction program of the State developed pursuant to section 134(b)(13), the amount specified pursuant to such section for such preceding year shall remain available for a second additional year for the purpose of paying the Federal share of the cost of construction of such facility.

[(b) Whenever the State plan approved in accordance with section 134 provides for participation of more than one State agency in administering or supervising the administration of designated portions of the State plan, the State may apportion its allotment among such agencies in a manner which, to the satisfaction of the Secretary, is reasonably related to the responsibilities assigned to such agencies in carrying out the purposes of this part. Funds so apportioned to State agencies may be combined with other State or Federal funds authorized to be spent for other purposes, provided the purposes of this part will receive proportionate benefit from the combination.

[(c) Whenever the State plan approved in accordance with section 134 provides for cooperative or joint effort between States or between or among agencies, public or private, in more than one State, portions of funds allotted to one or more such cooperating States may be combined in accordance with the agreements between the agencies involved.

[(d) The amount of an allotment to a State for a fiscal year which the Secretary determines will not be required by the State during the period for which it is available for the purpose for which allotted shall be available for reallotment by the Secretary from time to time, on such date or dates as he may fix, to other States with respect to which such a determination has not been made, in proportion to the original allotments of such States for such fiscal year, but with such proportionate amount for any of such other States being reduced to the extent it exceeds the sum the Secretary estimates such State needs and will be able to use during such period; and the total of such reductions shall be similarly reallotted among the States whose proportionate amounts were not so reduced. Any amount so reallotted to a State for a fiscal year shall be deemed to be a part of its allotment under subsection (a) for such fiscal year.

[(e) Of the sums appropriated pursuant to section 131, such amount as the Secretary may determine, but not more than 10 per centum thereof, shall be available for grants by the Secretary to public or nonprofit private agencies to pay up to 90 per centum of the cost of projects for carrying out the purposes of section 130 which in his judgment are of special national significance because they will assist in meeting the needs of the disadvantaged with developmental disabilities, or will demonstrate new or improved techniques for provision of services for such persons, or are otherwise specially significant for carrying out the purposes of this title.

NATIONAL ADVISORY COUNCIL ON SERVICES AND FACILITIES FOR THE DEVELOPMENTALLY DISABLED

[SEC. 133. (a)(1) Effective July 1, 1971, there is hereby established a National Advisory Council on Services and Facilities for the Developmentally Disabled (hereinafter referred to as the 'Council'), which shall consist of twenty members, not otherwise in the regular full-time employ of the United States, to be appointed by the Secretary without regard to the provisions of title 5, United States Code, governing appointments in the competitive civil service.

[(2) The Secretary shall from time to time designate one of the members of the Council to serve as Chairman thereof.

[(3) The members of the Council shall be selected from leaders in the fields of service to the mentally retarded and other persons with developmental disabilities, including leaders in State or local government, in institutions of higher education, and in organizations representing consumers of such services. At least five members shall be representative of State or local public or nonprofit private agencies responsible for services to persons with developmental disabilities, and at least five shall be representative of the interests of consumers of such services.

[(b) Each member of the Council shall hold for a term of four years, except that any member appointed to fill a vacancy occurring prior to the expiration of the term for which his predecessor was appointed shall be appointed for the remainder of such term, and except that, of the twenty members first appointed, five shall hold office for a term of four years, five shall hold office for a term of three years, five shall hold office for a term of two years, and five shall hold office for a term of one year, as designated by the Secretary at the time of appointment.

[(c) It shall be the duty and function of the Council to (1) advise the Secretary with respect to any regulations promulgated or proposed to be promulgated by him in the implementation of this title, and (2) study and evaluate programs authorized by this title with a view of determining their effectiveness in carrying out the purposes for which they were established.

[(d) The Council is authorized to engage such technical assistance as may be required to carry out its functions, and the Secretary shall, in addition, make available to the Council such secretarial, clerical, and other assistance and such statistical and other pertinent data prepared by or available to the Department of Health, Education, and Welfare as it may require to carry out such functions.

[(e) Members of the Council, while attending meetings or conferences thereof or otherwise serving on the business of the Council, shall be entitled to receive compensation at rates fixed by the Secretary, but at rates not exceeding the daily equivalent of the rate provided for GS–18 of the General Schedule for each day of such service (including travel time), and, while so serving away from their homes or regular places of business, they may be allowed travel expenses, including per diem in lieu of subsistence, as authorized by section 5703 of title 5, United States Code, for persons in the Government service employed intermittently.

[STATE PLANS

[SEC. 134. (a) Any State desiring to take advantage of this part must have a State plan submitted to and approved by the Secretary under this section.

[(b) In order to be approved by the Secretary under this section, a State plan for the provision of services and facilities for persons with developmental disabilities must—

[(1) designate (A) a State planning advisory council, to be responsible for submitting revisions of the State plan and transmitting such reports as may be required by the Secretary; (B) except as provided in clause (C), the State agency or agencies which shall administer or supervise the administration of the State plan and, if there is more than one such agency, the portion of such plan which each will administer (or the portion the administration of which each will supervise); and (C) a single State agency as the sole agency for administering or supervising the administration of grants for construction under the State plan, except that during fiscal year 1971, the Secretary may waive, in whole or in part, the requirements of this paragraph;

[(2) describe (A) the quality extent, and scope of services being provided, or to be provided, to persons with developmental disabilities under such other State plans for Federally assisted State programs as may be specified by the Secretary, but in any case including education for the handicapped, vocational rehabilitation, public assistance, medical assistance, social services, maternal and child health, crippled children's services, and comprehensive health and mental health plans, and (B) how funds allotted to the State in accordance with section 132 will be used to complement and augment rather than duplicate or replace services and facilities for persons with developmental disabilities which are eligible for Federal assistance under such other State programs;

[(3) set forth policies and procedures for the expenditure of funds under the plan, which, in the judgment of the Secretary are designed to assure effective continuing State planning, evaluation, and delivery of services (both public and private) for persons with developmental disabilities;

[(4) contain or be supported by assurances satisfactory to the Secretary that (A) the funds paid to the State under this part will be used to make a significant contribution toward strengthening services for persons with developmental disabilities in the various political subdivisions of the State in order to improve the quality, scope, and extent of such services; (B) part of such funds will be made available to other public or nonprofit private agencies, institutions, and organizations; (C) such funds will be used to supplement and, to the extent practicable, to increase the level of funds that would otherwise be made available for the purposes for which the Federal funds are provided and not to supplant such non-Federal funds; and (D) there will be reasonable State financial participation in the cost of carrying out the State plan;

[(5) (A) provide for the furnishing of services and facilities for persons with developmental disabilities associated with mental retardation, (B) specify the other categories of developmental disabilities (approved by the Secretary) which will be included in the State plan, and (C) describe the quality, extent, and scope of such services as will be provided to eligible persons;

[(6) provide that services and facilities furnished under the plan for persons with developmental disabilities will be in accordance with standards prescribed by regulations, including standards as to the scope and quality of such services and the maintenance and operation of such facilities, except that during fiscal year 1971, the Secretary may waive, in whole or in part, the requirements of this paragraph;

[(7) provide such methods of administration, including methods relating to the establishment and maintenance of personnel standards on a merit basis (except that the Secretary shall exercise no authority with respect to the selection, tenure of office, and compensation of any individual employed in accordance with such methods), as are found by the Secretary to be necessary for the proper and efficient operation of the plan;

[(8) provide that the State planning and advisory council shall be adequately staffed, and shall include representatives of each of the principal State agencies and representatives of local agencies and nongovernmental organizations and groups concerned with services for persons with developmental disabilities: *Provided*, That at least one-third of the membership of such council shall consist of representatives of consumers of such services;

[(9) provide that the State planning and advisory council will from time to time, but not less often than annually, review and evaluate its State plan approved under this section and submit appropriate modifications to the Secretary.

[(10) provide that the State agencies designated pursuant to paragraph (1) will make such reports, in such form and containing such information, as the Secretary may from time to time reasonably require, and will keep such records and afford such access thereto as the Secretary finds necessary to assure the correctness and verification of such reports;

[(11) provide that special financial and technical assistance shall be given to areas of urban or rural poverty in providing services and facilities for persons with developmental disabilities who are residents of such areas;

[(12) describe the methods to be used to assess the effectiveness and accomplishments of the State in meeting the needs of persons with developmental disabilities in the State;

[(13) provide for the development of a program of construction of facilities for the provision of services for persons with developmental disabilities which (A) is based on a statewide inventory of existing facilities and survey of need; and (B) meets the requirements prescribed by the Secretary for furnishing needed services to persons unable to pay therefor;

[(14) set forth the relative need, determined in accordance with regulations prescribed by the Secretary, for the several projects included in the construction program referred to in paragraph (13), and assign priority to the construction of projects, insofar as financial resources available therefor and for maintenance and operation make possible, in the order of such relative need;

[(15) specify the per centum of the State's allotment (under section 132) for any year which is to be devoted to construction of facilities, which per centum shall be not more than 50 per centum of the State's allotment or such lesser per centum as the Secretary may from time to time prescribe;

[(16) provide for affording to every applicant for a construction project an opportunity for hearing before the State agency;

[(17) provide for such fiscal control and fund accounting procedures as may be necessary to assure the proper disbursement of and accounting for funds paid to the State under this part; and

[(18) contain such additional information and assurances as the Secretary may find necessary to carry out the provisions and purposes of this part.

[(c) The Secretary shall approve any State plan and any modification thereof which complies with the provisions of subsection (b). The Secretary shall not finally disapprove a State plan except after reasonable notice and opportunity for a hearing to the State.

[APPROVAL OF PROJECTS FOR CONSTRUCTION

[SEC. 135. (a) For each project for construction pursuant to a State plan approved under this part, there shall be submitted to the Secretary, through the State agency designated pursuant to section 134(b)(1)(C), an application by the State or a political subdivision thereof or by a public or nonprofit private agency. If two or more agencies join in the construction of the project, the application may be filed by one or more of such agencies. Such application shall set forth—

[(1) a description of the site for such project;

[(2) plans and specifications thereof, in accordance with regulations prescribed by the Secretary;

[(3) reasonable assurance that title to such site is or will be vested in one or more of the agencies filing the application or in a public or nonprofit private agency which is to operate the facility;

[(4) reasonable assurance that adequate financial support will be available for the construction of the project and for its maintenance and operation when completed;

[(5) reasonable assurance that all laborers and mechanics employed by contractors or subcontractors in the performance of work on construction of the project will be paid wages at rates not less than those prevailing on similar construction in the locality as determined by the Secretary of Labor in accordance with the Davis-Bacon Act, as amended (40 U.S.C. 276a—276a-5); and the Secretary of Labor shall have with respect to the labor standards specified in this paragraph the authority and functions set forth in Reorganization Plan Numbered 14 of 1950 (15 F.R. 3176; 5 U.S.C. 133z-15) and section 2 of the Act of June 13, 1934, as amended (40 U.S.C. 276c); and

[(6) a certification by the State agency of the Federal share for the project.

[(b) The Secretary shall approve such application if sufficient funds to pay the Federal share of the cost of construction of such project are available from the allotment to the State, and if the Secretary finds (1) that the application contains such reasonable assurances as to title, financial support, and payment of prevailing rates of wages and overtime pay, (2) that the plans and specifications are in accord with regulations prescribed by the Secretary, (3) that the application is in conformity with the State plan approved under this part, and (4) that the application has been approved and recommended by the State agency and is entitled to priority over other projects within the State in accordance with the State's plan for persons with developmental disabilities and in accordance with regulations prescribed by the Secretary.

[(c) No application shall be disapproved until the Secretary has afforded the State agency an opportunity for a hearing.

[(d) Amendment of any approved application shall be subject to approval in the same manner as the original application.

[WITHHOLDING OF PAYMENTS FOR CONSTRUCTION

[SEC. 136. Whenever the Secretary, after reasonable notice and opportunity for hearing to the State planning and advisory council designated pursuant to section 134(b)(1)(A) and the State agency designated pursuant to section 134(b)(1)(C) finds—

[(a) that the State agency is not complying substantially with the provisions required by section 134(b) to be included in the State plan, or with regulations of the Secretary;

[(b) that any assurance required to be given in an application filed under section 135 is not being or cannot be carried out;

[(c) that there is a substantial failure to carry out plans and specifications related to construction approved by the Secretary under section 135; or

[(d) that adequate funds are not being provided annually for the direct administration of the State plan,

the Secretary may forthwith notify such State council and agency that—

[(e) no further payments will be made to the State for construction from allotments under this part; or

[(f) no further payments will be made from allotments under this part for any project or projects designated by the Secretary as being affected by the action or inaction referred to in paragraph (a), (b), (c), or (d) of this section;

as the Secretary may determine to be appropriate under the circumstances; and, except with regard to any project for which the application has already been approved and which is not directly affected, further payments for construction projects may be withheld, in whole or in part, until there is no longer any failure to comply (or to carry out the assurance or plans and specifications or to provide adequate funds, as the case may be), or if such compliance (or other action) is impossible, until the State repays or arranges for the repayment of Federal moneys to which the recipient was not entitled.

[PAYMENTS TO THE STATES FOR PLANNING, ADMINISTRATION AND SERVICES

[SEC. 137. (a)(1) From each State's allotments for a fiscal year under section 132, the State shall be paid the Federal share of the expenditures, other than expenditures for construction, incurred during such year under its State plan approved under this part. Such payments shall be made from time to time in advance on the basis of estimates by the Secretary of the sums the State will expend under the State plan, except that such adjustments as may be necessary shall be made on account of previously made underpayments or overpayments under this section.

[(2) For the purpose of determining the Federal share with respect to any State, expenditures by a political subdivision thereof or by nonprofit private agencies, organizations, and groups shall, subject to such limitations and conditions as may be prescribed by regulations, be regarded as expenditures by such State.

[(b)(1) Except as provided in paragraph (2), the "Federal share" with respect to any State for purposes of this section for any fiscal year shall be 75 per centum of the expenditures, other than expenditures for construction, incurred by the State during such year under its State plan approved under this part during each of the fiscal years ending June 30, 1971, and June 30, 1972, and 70 per centum of such nonconstruction expenditures during the fiscal year ending June 30, 1973.

[(2) In the case of any project located in an area within a State determined by the Secretary to be an urban or rural poverty area, the "Federal share" with respect to such project for purposes of this section for any fiscal year may be up to 90 per centum of the expenditures, other than expenditures for construction, incurred by the State during such year under its State plan approved under this part with respect to such project for the first twenty-four months of such project, and 80 per centum of such nonconstruction expenditures for the next twelve months.

[WITHHOLDING OF PAYMENTS FOR PLANNING, ADMINISTRATION, AND SERVICES

[SEC. 138. Whenever the Secretary, after reasonable notice and opportunity for hearing to the State planning and advisory council and the appropriate State agency, designated pursuant to section 134(b)(1) finds that—

[(a) there is a failure to comply substantially with any of the provisions required by section 134 to be included in the State plan; or [(b) there is a failure to comply substantially with any regulations of the Secretary which are applicable to this part,

the Secretary shall notify such State council and agency or agencies that further payments will not be made to the State under this part (or, in his discretion, that further payments will not be made to the State under this part for activities in which there is such failure), until he is satisfied that there will no longer be such failure. Until he is so satisfied, the Secretary shall make no further payment to the State under this part, or shall limit further payment under this part to such State to activities in which there is no such failure.

[REGULATIONS

[SEC. 139. The Secretary, as soon as practicable, by general regulations applicable uniformly to all the States, shall prescribe—

[(a) the kinds of services which are needed to provide adequate programs for persons with developmental disabilities, the kinds of services which may be provided under a State plan approved under this part, and the categories of persons for whom such services may be provided;

[(b) standards as to the scope and quality of services provided for persons with developmental disabilities under a State plan approved under this part;

[(c) the general manner in which a State, in carrying out its State plan approved under this part, shall determine priorities for services and facilities based on type of service, categories of persons to be served, and type of disability, with special consideration being given to the needs for such services and facilities in areas of urban and rural poverty; and

[(d) general standards of construction and equipment for facilities of different classes and in different types of location.

After appointment of the Council, regulations and revisions therein shall be promulgated by the Secretary only after consultation with Council.

[NONDUPLICATION

[SEC. 140. (a) In determining the amount of any payment for the construction of any facility under a State plan approved under this part, there shall be disregarded (1) any portion of the costs of such construction which are financed by Federal funds provided under any provision of law other than this part, and (2) the amount of any non-Federal funds required to be expended as a condition of receipt of such Federal funds.

[(b) In determining the amount of any State's Federal share of expenditures for planning, administration, and services incurred by it under a State plan approved under this part, there shall be disregarded (1) any portion of such expenditures which are financed by Federal funds provided under any provision of law other than this part, and (2) the amount of any non-Federal funds required to be expended as a condition of receipt of such Federal funds.]

Senator **Randolph.** The committee stands in recess.

[Whereupon, at 11:20 a.m., the subcommittee recessed, subject to the call of the Chair.]

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